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LONG- AND SHORT-TERM FREQUENT ATTENDERS IN PRIMARY HEALTHCARE – PERCEPTIONS OF PATIENT-CENTREDNESS, INTERACTION AND ENCOUNTERS WITH HEALTHCARE PERSONNEL

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**Abstract**

The purpose of the study was to describe and explain the perceptions of long- and short-term frequent attenders (FAs) regarding patient-centredness, interaction and encounters with healthcare personnel in primary healthcare.

The study consisted of four original publications. Publication I compared long- (n=132) and short-term FAs’ (n=645) characteristics using cross-sectional Northern Finland Birth Cohort 1966 data from the 46-year follow-up study. The data was analysed using descriptive statistics and multivariate logistic regression analyses. Publications II and III compared long- (n=234) and short-term FAs’ (n=261) perceptions of patient-centredness (the Patient-Centred Primary Care instrument, PCPC) and patient-professional interaction (the Patient-Professional Interaction Questionnaire, PPIQ), respectively, using cross-sectional survey data collected in January–July 2020. The data was analysed using the Mann-Whitney U test and multigroup confirmatory factor analysis (MGCFA). Publication IV synthesised FAs’ experiences of encounters with healthcare personnel through a systematic review of qualitative studies (n=6). The data was synthesised by meta-aggregation.

Self-reported poor health was an explaining factor, especially for long-term FAs. Relative to short-term FAs, depression and low income were associated with long-term FAs. Long-term FAs' perceptions of patient-centredness (patients’ preferences, physical comfort, coordination of care, continuity and transition, emotional support, access to care, information and education, family and friends) and patient-professional interaction (patient involvement) were inferior to those of short-term FAs. Among long-term FAs, young age and female gender negatively correlated with patient-centredness, while for short-term FAs the same was true for young age and high education. MGCFA indicated a good model fit for PCPC and PPIQ. The systematic review indicated that difficulties in resolving FAs’ situations may create service circles, making patients frustrated with their situation. The FAs’ own expertise should be recognised and valued alongside the expertise of healthcare professionals when performing collaborative care. Disparagement and a lack of empathy may make FAs feel misunderstood and unappreciated. FAs should be recognised as individuals by taking their circumstances into account and providing support accordingly.

**Keywords:** encounter, frequent attender, patient-centredness, patient-professional interaction, primary healthcare

Tiivistelmä
Tutkimuksen tarkoituksena oli kuvailla ja selittää pitkä- ja lyhyaaiakaisesti paljon palveluja tarvitsevien asiakkaiden näkemyksiä asiakaslähtöisyydestä, vuorovaikutuksesta ja kohtaamisesta terveydenhuollon henkilöstön kanssa perusterveydenhuollossa.


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Abbreviations

CFI          Comparative fit index
CI           Confidence interval
ConQual      Rating of confidence in the qualitative synthesised finding
FA           Frequent attender
JBI          Joanna Birggs Institute
MGCFA        Multigroup confirmatory factor analysis
NCI          Noncentrality index
NFBC1966     Northern Finland Birth Cohort 1966
PCPC         Patient-centred primary care
PPIQ         Patient-professional interaction questionnaire
RMSEA        Root mean square error of approximation
THL          Finnish Institute for Health and Welfare
TLI          Tucker-Lewis fit index
15D          Health-related quality of life instrument
List of original publications

This thesis is based on the following publications, which are referred throughout the text by their Roman numerals:


Original publications are not included in the electronic version of the dissertation.
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1 Introduction

Even though overall morbidity has decreased in Finland during the 21st century, the ageing of the population increases needs for healthcare services (THL, 2019a). In Finland in 2018, a total of 25.1 million visits were made to primary healthcare centres by 69% of the population. Of visits, 26% were made to physicians and 74% to other healthcare professionals (THL, 2019b). A small share of patients – frequent attenders (FAs) – account for a large share of visits, creating a significant workload: 10% of patients cause 81% of social and healthcare costs (Leskelä et al., 2013). The high number of consultations indicates that FAs’ care needs are not adequately met. Healthcare professionals feel they are not always able to provide the care that would improve the FAs’ health or decrease their consultation frequency, resulting in feelings of helplessness (Hujala & Lammintakanen, 2018.) Simultaneously there are recruitment and retention problems among healthcare professionals (Li et al., 2020; Nokela et al., 2021), which is why it is essential to target healthcare resources cost-effectively and to examine how healthcare services can be developed to better respond to FAs’ needs.

Although some attributes seem to be common among FAs regardless of the healthcare sector, it is important to consider the way the care is organised when frequent attendance is examined. For example, the offset of frequent attendance and need for care is different in first-point-of-contact care and specialised healthcare. Primary healthcare in Finland has a gatekeeping role for accessing more expensive and more extensive specialist care services. The gatekeeper role is important in responding to care needs that can be solved in more easily accessible primary care to prevent the overloading of specialised care and health conditions which do not require specialised care. (Keskimäki et al., 2019.) In Finland, one of the aims of the social and healthcare reform is to move the focus of care to preventive primary care, which is why it is important to understand how Finnish primary healthcare is currently able to respond to care needs (Valtioneuvosto, 2022).

Although previous international studies have examined frequent attendance in the primary care context, Finnish primary care has distinctive features that make it difficult to generalise international results to the Finnish primary care context (Keskimäki et al., 2019). In addition, if there are problems in accessing adequate primary care (Hudon et al., 2016), FAs seek care from different healthcare sectors, often burdening emergency care (Burns, 2017).

Frequent attendance has been widely studied, and several attributes have been found to be associated with FAs (Giannouchos et al., 2019; Hajek et al., 2021;
Kivelä et al., 2018; Marcoux et al., 2017; Vedsted & Christensen, 2005; Wammes et al., 2018; Welzel et al., 2017). However, there is a need to identify factors related to how care is organised, considering FAs’ needs. The high number of consultations and the complexity of care needs of FAs lead to an increased workload for healthcare professionals (Alahuhta & Niemelä, 2017). On the other hand, the insufficiency of the time allocated for consultations hampers the ability of healthcare professionals comprehensively to consider FAs’ care needs. This further complicates the setting of care goals. (Smeets et al., 2020.)

Most studies focus on frequent attendance without considering whether it is temporary or prolonged. However, frequent attendance is often only temporary, and the focus of identification and interventions should be on FAs with a prolonged high need for services (Koskela, 2008; Koskela et al., 2010; Luutonen et al., 2019; Malins et al., 2016; Pymont & Butterworth, 2015). In order to identify FAs with long-term care needs, to plan interventions and organise care suitable for long-term FAs in particular, it is necessary to identify the attributes of long-term FAs and how the healthcare system supports their needs.

This study is positioned in the field of health management science, focusing on examining healthcare system in particular. The patients’ role in the health system and service assessment is one of the research interests of health management science. External factors affect the way in which healthcare services are arranged. (Niiranen & Lammintakanen, 2011.) Currently the changing attitudes of patients towards customership and patient-centredness in healthcare, and the increased interest in improving care for FAs as part of the social and health services reform are examples of external factors to be considered when examining the patients’ role in healthcare. These require rearrangements from healthcare organisations and in relation to the content of the provided care.

The purpose of this study was to describe and explain long- and short-term frequent attenders’ perceptions of patient-centredness, interaction and encounters with healthcare personnel in primary healthcare. The aim of the study was to increase knowledge of frequent attenders’ individual and diverse healthcare needs and perceptions of healthcare services, which can be used for improving the ability of healthcare services and professionals to enhance the care provided to frequent attenders. The study consists of four original publications.
2 Frequent attendance in primary healthcare

This chapter describes the central literature regarding the phenomenon of frequent attendance and defines the main concepts of the dissertation. For this purpose, a literature search was conducted in the following databases: CINAHL, Scopus and PubMed (Medline) with publication dates within 2000–2022. The database searches were conducted in several separate phases with respect to each original publication’s purposes, with complementary searches for this compilation.

The search terms were related to the main concepts of the dissertation, using the search terms patient-centredness, person-centredness, patient-professional interaction, patient-nurse interaction, patient-physician interaction and encounter. Regarding FAs, the search terms included frequent attender, frequent visitor, high-need and high-cost patient, and high utiliser. Controlled vocabulary (e.g. MeSH terms), free search terms and truncations were used. Original publication IV provides the results of qualitative studies examining FAs’ experiences of encounters with healthcare personnel.

2.1 Definitions for frequent attendance and related factors

Various definitions used for frequent attendance

Frequent attendance refers to a phenomenon in which a patient group has higher needs for healthcare services than average health service users. Literature reviews have found that in general practice, 30–50% of consultations are made by 10% of patients (Vedsted & Christensen, 2005), whereas in emergency departments, 21–28% of visits are made by 5–8% of patients (LaCalle & Rabin, 2010). In Finland, 10% of the population accounts for 81% of social and public primary healthcare costs (Leskelä et al., 2013).

There is no consistent definition used for frequent attendance. This variation of definitions complicates coherent identification of FAs and attributes associated with frequent attendance (Vedsted & Christensen, 2005). In Finland, identification of FAs in health centres is often based on the expertise of nurses and physicians, and systematic ways for identification are lacking, although the presence of such identification would be essential from the viewpoint of determining the healthcare costs required to responding to frequent attendance (Valtiontalouden tarkastusvirasto, 2017).
The definitions are based either on the number of visits to a certain healthcare sector, on the healthcare costs caused, or on belonging to the ‘top’ group of healthcare users. When the number of healthcare visits is considered, there is no common understanding of what is considered ‘frequent’. In primary and emergency care, the definition varies from three to 24 consultations in one year, whereas the considered time span may vary from a certain number of months to multiple years (Kivelä et al., 2018; LaCalle & Rabin, 2010). In Finnish studies conducted in primary healthcare, eight or more visits in a given year has been used as a definition (Hirsikangas, 2021; Koskela et al., 2010). In inpatient hospital care, four hospital admissions over a year are usually considered frequent hospitalisation (Huang et al., 2020; Springer et al., 2017). When the definition for FAs is based on the healthcare costs caused, patients belonging to the top 5–10% of costs caused by a certain patient population are deemed to be FAs (Wammes et al., 2018). A similar definition is used in terms of top healthcare visitors: for example belonging to the top 10% or 25% of healthcare visitors can mean being a FA (Leskelä et al., 2013; Luciano et al., 2010; Wammes et al., 2018). Smits et al. (2014) have argued that if the definition of FA is based on a percentual share of the patient population, the patients deemed as FAs are most likely to be elderly females (if no stratification is made, more elderly and female patients are included), and they suggest using gender and age stratification when identifying FAs. However, if the definition of FA is based on number of healthcare visits during a specific time period, the limit for frequent attendance is more distinct.

In addition to different cut-offs being used in defining FAs, there are also differences as to which services are taken into account. In general practice, the definition is often based solely on physicians’ visits (Koskela et al., 2010). However, because FAs often have a need for multiprofessional care, studies have based their definitions on e.g. visits to physicians, nurses and psychologists (Reho et al., 2018). Some studies have also considered social care visits in addition to primary healthcare visits, when the focus of research has been on the need for integrated services (Hujala et al., 2019; Ylitalo-Katajisto, 2019). Often, when the definition is based on the number of visits, it refers to visits made to a specific healthcare sector. Studies have rarely used information from several sectors. Information systems may not support information exchanges between, for example, social care and primary care, or between primary and specialist care (Alahuhta & Niemelä, 2017). However, the current health and social service reform in Finland is aiming to rectify this shortcoming.
Varying concepts are used for frequent attendance; for example, frequent attenders (FAs), high utilisers, high-need and high-cost patients, heavy users, and frequent visitors are all terms used for describing patients with increased healthcare needs. Although many of the concepts describing FAs refer to high use of healthcare services, in this study frequent attendance originates from an increased need for healthcare services. The definition used for FAs in this study, similarly to most of the previous studies, is based on the number of healthcare visits. Thus, the number of visits is objectively observed. However, it is not necessarily possible for healthcare professionals to objectively identify whether or not the increased use of healthcare services is based on the patient’s needs (i.e. there may not be a clear reason for attendance). Thus, this study considers that a patient’s need for care and seeking of care originates from their own experience of need.

Previously identified factors associated with frequent attendance

Many attributes have been found to be associated with frequent attendance, and multiple literature reviews have been conducted on the topic in primary care (Hajek et al., 2021; Haroun et al., 2016; Smits et al., 2008; Welzel et al., 2017) and emergency care (Althaus et al., 2011; Giannouchos et al., 2019; Moe et al., 2016, 2017; van den Heede & van de Voorde, 2016). In Finland, frequent attendance has been examined in primary care (Hirsikangas, 2021; Kaattari et al., 2015; Kivelä, 2019; T. Koskela, 2008), primary health and social care (Hujala et al., 2019; Hujala & Lammintakanen, 2018; Leskelä et al., 2013; Ylitalo-Katajisto, 2019), emergency care (Levola et al., 2019), special care (Leskelä et al., 2015) and occupational healthcare (Reho, 2020). Recent doctoral theses on frequent attendance have been conducted in the field of nursing science (Hirsikangas, 2021; Kivelä, 2019), medicine (Reho, 2020) and health management science (Ylitalo-Katajisto, 2019). The theses provided information on how health coaching can promote FAs’ health (Kivelä, 2019); on FAs’ adherence to health regimens and the effectiveness of case management (Hirsikangas, 2021); on what kinds of customer profiles can be identified for FAs and the integration of social and healthcare services as part of FA care (Ylitalo-Katajisto, 2019); and on frequent attendance in occupational healthcare and its association with work disability (Reho, 2020). Koskela (2008) examined the characteristics associated with long-term FAs in particular.

Having multiple (Kivelä et al., 2018) or individual chronic health conditions is a common reason for frequent attendance. Conditions such as diabetes (Jorgensen et al., 2016), cardiac diseases, respiratory conditions and mental health conditions
(Buja et al., 2018) are associated with frequent attendance. Physical limitations caused by health conditions can limit FAs’ everyday lives (Brodeur et al., 2020; Kolk et al., 2021) and put them at a risk of prolonged sickness absences (Reho et al., 2019) and of retiring with a disability pension (Reho et al., 2021).

In terms of lifestyle factors, associations have been found between FAs and being overweight, low physical activity and higher-than-recommended alcohol consumption (Jørgensen et al., 2016). Low quality of life (LaCalle & Rabin, 2010; Strömbom et al., 2019), self-perceived poor health (Kaattari et al., 2015; LaCalle & Rabin, 2010; Luppa et al., 2020), dissatisfaction with the current life situation, somatization (Kivelä et al., 2018; LaCalle & Rabin, 2010), anxiety (Kujanpää et al., 2014) and medically unexplained symptoms (Rasmussen et al., 2008; Warner et al., 2017) are also explaining factors for frequent attendance. Psychological distress (i.e. how an individual is able to respond to stressors resulting from inability to cope and feelings of discomfort) is more common among FAs, and if psychological distress increases, it increases the risk of becoming a FA over time (Margo-Dermer et al., 2019). Due to increased care needs and healthcare visits, frequent attendance may cause feelings of stress and insecurity for FAs. Health problems are often present for many weeks, or the severity of symptoms may increase before attending healthcare. (Kolk et al., 2021.)

In primary care, economic and social difficulties (Kivelä et al., 2018; Luppa et al., 2020) have been identified as explaining factors for frequent attendance. Health conditions can have a negative impact on FAs’ social relationships and how FAs view the effects of their health conditions on others; FAs may feel they and their health conditions burden their family and friends, as well as the society (Brodeur et al., 2020). Frequent healthcare attenders have also been found often to have a need for social services (Ylitalo-Katajisto, 2019) and employment services (Koivisto & Tiirinki, 2020).

FAs are often female (Ferrari et al., 2008; Jørgensen et al., 2016), unemployed (Jørgensen et al., 2016), with a lower educational level (Ferrari et al., 2008; Jørgensen et al., 2016; Reho et al., 2021) or elderly (Ferrari et al., 2008; Welzel et al., 2017). Among elderly FAs, chronic health conditions, multimorbidity (Welzel et al., 2017), mental health conditions (e.g. dementia) and feelings of loneliness (Cruwys et al., 2018; Hand et al., 2014) are some of the explaining factors for increased care needs. Older FAs in primary care have reported needs for services related to social issues, such as advice on social relations or information on beneficial healthcare services (Hand et al., 2014).
It should be noted that although the aforementioned characteristics have been found to be associated with FAs, they are not generalisable to every FA. Also, there are no unambiguous characteristics explaining frequent attendance. Rather, a combination of characteristics results in frequent attendance. Characterisation supports the identification of patients who may have increased needs for services. In line with this, the identification of FA characteristics has led to an examination of FA subgroups, such as FAs with multimorbidity, unexplained medical symptoms (Taylor et al., 2012) or elderly FAs (Welzel et al., 2017). Similarly, interventions have been conducted in response to definite FA subgroups’ care needs (Haroun et al., 2016).

2.2 Frequent attendance as a phenomenon changing over time

Definitions based on attendance over a one-year period are most commonly used in FA studies. Some of the studies take into account healthcare visits made over two or three years, considering e.g. at least 15 visits during 30 months (Kivelä et al., 2018). However, these studies do not consider whether the FA status persists for multiple years, i.e. whether the frequent attendance is long-term. The visits may or may not occur evenly during the time period under review. For example, most of the visits may be made at the beginning of the time period and the need for care may decrease after this high attendance. In primary care, only 40% of FAs experience a high need for services that persists for two years (Rifel et al., 2013), which indicates that it is necessary to consider whether frequent attendance is a temporary or long-term phenomenon. Long-term FAs’ share of overall general practice visits is 13–16% (Pymont & Butterworth, 2015), and when frequent attendance continues for several years, the costs for healthcare are higher (Johnson et al., 2015).

In their definitions of long-term FAs, studies usually define FA status based on attendance rates over three consecutive years. For example, a patient is a FA over three out of three years (Hwang et al., 2015; Reho et al., 2018; Smits et al., 2013) or at least three out of four years (Koskela et al., 2010). As in the case for FA definitions overall, the criteria vary, being a percentage-based definition related to costs caused (Hwang et al., 2015), or certain share of the patient population (Smits et al., 2014), or how many healthcare visits have been made (Kanzaria et al., 2017; Koskela et al., 2010). Thus, as with FA definitions in general, differences in definitions make it relatively difficult to draw comparisons between study outcomes.
Systematic reviews examining the effectiveness of interventions targeted at FAs in primary care show that the interventions do not explicitly demonstrate a possibility of decreasing the need for healthcare services (Smits et al., 2008). In emergency care, although interventions have reduced visits, results indicating their effectiveness are contradictory (van den Heede & van de Voorde, 2016). Long-term FAs have more potential as candidates for interventions compared to targeting interventions to FAs in general. When frequent attendance is only short-term, interventions may not have relevance (or at least may not be cost-effective) in reducing healthcare visits (Smits et al., 2013). In contrast, long-term FAs account for the largest proportion of healthcare costs, which indicates that they would benefit from targeted interventions (Birmingham et al., 2020). Most of the previous interventions have involved FAs in general, while only few interventions targeted at long-term FAs have been implemented (Luutonen et al., 2019; Malins et al., 2016). The focus of research has been on frequent attendance in general, and although numerous attributes have been found to be associated with frequent attendance, only some of them related to long-term FAs in particular. In order to develop effective interventions for long-term FAs, it is essential to identify the characteristics of FAs with a prolonged high need for care. This also requires a distinction between long- and short-term FAs.

Attributes associated with long-term FAs are somewhat inconsistent. A systematic review examining long-term FAs in primary healthcare identified that lower age, unemployment, self-reported poor health, physical illnesses and low physical functional ability were consistently associated with long-term FAs (Hajek et al., 2021). In contrast, increasing age has been found to be associated with FAs (McDermott et al., 2020). Also depressive symptoms (Koskela et al., 2010; Pymont & Butterworth, 2015; Smits et al., 2014) and female gender (Kanzaria et al., 2017; Koskela et al., 2010; Pymont & Butterworth, 2015; Reho et al., 2018) have been identified as predictors of long-term frequent attendance.

Only a couple of previous studies have compared the characteristics of short-term and long-term FAs (Koskela et al., 2010; Pymont & Butterworth, 2015; Reho et al., 2018). Chronic health conditions and female gender are attributes associated with long-term FAs identified by both of these studies. In addition, low patient satisfaction (Koskela et al., 2010) and depression (Pymont & Butterworth, 2015) have been found to be associated with long-term FAs.
2.3 Patient-centredness

Over time, the patient’s role in healthcare has shifted from care led by a healthcare professional to care planning and treatment in which the patient has a more active role. Patient-centredness is a practice approach which indicates this change. (McColl-Kennedy et al., 2017.) Different dimensions have been associated with patient-centredness but there does not seem to be an unequivocal definition for the concept. In general, it refers to an approach that not only focuses on disease treatment specifically but also considers a wider patient perspective. For example, according to a Finnish dictionary of social and healthcare management (THL, 2021), patient-centredness is defined as follows:

*Approach where service enablers see clients as individuals and active bodies, organise their activities based on the clients’ needs and resources and enable the clients to act as equal partners with experts and professionals.*

In the aforementioned definition, a service enabler refers to a body that organises and provides health and social services. In practice, it can be, for instance, a wellbeing services county or an organisation that actually delivers services. (THL, 2021.) Thus, patient-centredness can be approached from a wider organisational perspective or as a way of delivering care during a consultation. Aspects of the broader health system perspective include considering the expenses of the care (in case the patient wishes for particular care but it is not considered necessary from the professional viewpoint) (Brickley et al., 2021). As noted by Kitson et al. (2013), the context of care is not often identified as a dimension of patient-centredness. They argue that the variation in conceptualisations of patient-centredness is partly due to the fact that there are differences as to which aspects are considered core elements of patient-centred care within various branches of science. Although there is consistency as to which aspects are considered essential parts of patient-centredness within medicine, nursing and health policy, the two latter branches of science focus on both the wider system perspective and the professional-patient relationship, while medicine focuses on the relationship aspect. (Kitson et al., 2013.)

The US Institute of Medicine (2001) and the Picker Institute (1993) have used wider definitions and identified similar dimensions of patient-centredness: respectfulness towards patients’ values, preferences and expressed needs; providing information, communication and education; physical comfort; providing emotional support; and involving family and friends. The Institute of Medicine (2001) has classified coordinated and integrated care under one dimension, while
the Picker Institute (1993) categorises coordination of care as one dimension, and ‘continuity and transition between healthcare settings’ as a separate dimension. The Picker Institute also identifies access to care as one of the dimensions of patient-centredness.

Concept analyses have identified similar dimensions of patient-centredness. There is a shared understanding regarding some aspects: considering patients’ individual needs; patient involvement in care; and the biopsychological perspective are commonly identified dimensions (Castro et al., 2016; Eklund et al., 2019; Langberg et al., 2019). Recognition of individual needs and the patient-as-person approach (Langberg et al., 2019; Mead & Bower, 2000) require identification of what preferences (Eklund et al., 2019) and expectations (Castro et al., 2016) the patient has for their care. In practice, these aspects are realised in a care plan (Kitson et al., 2013). Also, the possible effects of the patient’s individual situation on their health condition should be considered: the same health condition or its impacts on life may be experienced differently by different patients (Langberg et al., 2019; Mead & Bower, 2000). Although optimising disease treatment is one of the goals of patient-centredness, it may lead to lack of consideration of a patient’s individual needs, while the healthcare professional’s perspective is emphasised instead (Pel et al., 2021).

The dimension of patient involvement in care has varying constructs: individual patient participation (Castro et al., 2016), shared decision-making (Eklund et al., 2019) and sharing power and responsibility (Langberg et al., 2019; Mead & Bower, 2000). Because the patient has personal knowledge of their own situation and needs, patients must be actively involved in deciding on the desired care outcomes (Castro et al., 2016). Concepts of empowerment, shared decision-making or ways of encouraging patient participation have been used for describing the idea of ‘sharing power and responsibility’, meaning that the patient is not seen as a passive care receiver but rather as an active participant in care decisions. From a healthcare professional, this requires empowering the patient to participate by asking questions. (Langberg et al., 2019.) In contrast to involving patients, in the physician-centred consulting style, the physician’s medical knowledge and direction-giving are highlighted (Mead & Bower, 2000). Healthcare professionals should pay attention to the understandability of the given information (THL, 2021).

The biopsychological perspective acknowledges a comprehensive view of health that considers biological, psychological and social health (Castro et al., 2016; Langberg et al., 2019). Regarding the ‘biomedical model’, which is restricted to disease diagnosis, the biopsychological perspective can cover a wider range of
health problems, i.e. in situations in which an illness affects not only biological health but also psychological and social health (Mead & Bower, 2000).

Other dimensions of patient-centredness include a therapeutic relationship or alliance. Through a therapeutic relationship, positive outcomes such as adherence to care can be achieved (Mead & Bower, 2000). It prioritises respectful communication, which requires two-way interaction (Eklund et al., 2019), where the patient’s experiential knowledge and the physician’s medical knowledge are exchanged (Castro et al., 2016; Kitson et al., 2013) and can be used in planning, implementing and evaluating care (Langberg et al., 2019). In line with the dimension of the therapeutic relationship, empathy (emotional support, compassion), a respectful attitude towards the patient, and engagement by being committed and present have been itemised as aspects of patient-centredness (Eklund et al., 2019).

In terms of patient-centredness, coordination of care requires coordination across changing situations, services and providers (Eklund et al., 2019). Kitson et al. (2013) also noted the importance of multiprofessionality in providing patient-centred care. The complexity of the health system negatively impacts on the coordination of care if patients are required independently to find out where their care should be coming from, or if they have to wait for care due to referral issues, and this further hampers patient-centredness (Brickley et al., 2021). In line with physical comfort being an aspect of patient-centredness (US Institute of Medicine, 2001), Brickley et al. (2021) identified the practice environment as an element; reception staff can influence feelings of being welcomed and the physical setting of the practice can improve patient-centredness.

Because of the conceptual ambiguity, there are difficulties not only in operationalising the concept of patient-centredness but also in measuring and comparing the results of studies examining the phenomenon (Castro et al., 2016). Although instruments measuring patient-centredness include similar dimensions, they are based on different conceptualisations of patient-centredness and thus some of them measure broader dimensions of patient-centredness while others may focus only on aspects such as the decision-making process (Hudon et al., 2011; Köberich & Farin, 2015).

Patient-centredness has been found to have several positive outcomes related not only to patient care but also to organisational factors. Improvements in patient-centredness in primary healthcare decrease visits to emergency care (Hearld & Alexander, 2012), needs for specialist care, hospitalisations, clinical tests and medical costs (Bertakis & Azari, 2011). Improvements have been found in
adherence to care (Robinson et al., 2008), self-management, satisfaction with care (Rathert et al., 2013), lower likelihood for delays in care and care coordination (Hearld & Alexander, 2012). Various patient-centred care interventions have been targeted at patients (e.g. interventions aiming at improving patient participation in care or physical health by acknowledging patients’ individual needs) and healthcare professionals (e.g. training on how to implement patient-centred care during consultations). Patient-centred interventions improve patients’ quality of life, self-care and knowledge of their health condition, their physical and psychological health (e.g. anxiety). (Park et al., 2018.) For healthcare professionals, it is possible through patient-centred interventions to improve job satisfaction, the quality of care (Park et al., 2018), the level of empathy, abilities to provide clear information about treatment options, and consideration of patients’ concerns and conditions, among others (Dwamena et al., 2012).

Through interviews with healthcare professionals, Hower et al. (2019) have identified determinants that improve or hinder the implementation of patient-centredness during consultations. Organisational-level determinants include, for example, using patient feedback and reviewing patient cases in care teams as a way of gathering information about the level of patient-centredness. Shortages of healthcare professionals and high workloads, which result in a lack of time per patient and increased waiting times, are some of the factors hampering patient-centredness. At the individual level, communication skills and overall professional competence are important factors in providing patient-centred care. Also, a healthcare professional’s attitude towards providing patient-centred care during consultations and support received from colleagues and management (e.g. enough time provided for caring for individual patients) were considered important. (Hower et al., 2019.) When providing patient-centred care, healthcare professionals emphasise most highly the importance of prioritising patients’ preferences, treating patients with respect, and improving shared decision-making (Berghout et al., 2015).

2.4 Patient-professional interaction

There is no unequivocal definition of patient-professional interaction (also called patient-physician or patient-nurse interaction), and it is often used interchangeably with the term ‘communication’. However, interaction is more of an observable behaviour that happens during communication. (Fleischer et al., 2009.) Communication skills as part of interaction and attached social meanings are a
requisite for establishing a relationship between the patient and the healthcare professional (Stoddart, 2012). Williams & Irurita (2004) examined the effects and attributes of therapeutic and non-therapeutic interpersonal interactions from the patient perspective. While therapeutic interpersonal interactions improve emotional comfort by facilitating the patient’s feeling of personal control, non-therapeutic interaction between the patient and the healthcare professional causes emotional discomfort. The following dimensions can be identified as part of therapeutic interaction: verbal (e.g. engaging the patient in conversation) and non-verbal interaction, information provision, developing a relationship, being available, and showing professional competence. (Williams & Irurita, 2004.) Opportunities for patient participation, promoting patients’ competencies and the healthcare professional’s ability to demonstrate empathy are further important aspects of interaction to be considered (Fleischer et al., 2009).

Creating a relationship between the patient and the professional does not seem to be dependent of the number or the duration of interactions. Nurses need competence in helping patients feel comfortable, recognising patients’ care needs and affording care according to these needs, being respectful towards patients’ life experiences, and helping patients to achieve expectations related to health (Chung et al., 2018). Interaction can facilitate the building of a relationship and trust between the patient and healthcare professional (Johnsson et al., 2021) and productive interactions are associated with patients’ wellbeing and quality of care (Cramm & Nieboer, 2015).

2.5 Patient encounter

The term encounter describes a deeper level of interaction (Holopainen et al., 2019) and can be considered as a form of social interaction (Johnsson et al., 2021). Salokekkilä (2011) has identified factors that from a patient’s perspective predict the success or failure of patient encounters. The physician’s competence (medical and communication skills and the ability to consider the patient’s individual situation), a caring attitude, and taking the patient seriously are required for a successful encounter. Also respect and trust towards physicians and their expertise, sharing of information between the patient and the physician during the consultation, and continuity of the care relationship were identified as important factors. In contrast, factors associated with failed patient encounters included the physician’s indifference (ignoring the patient or demonstrating a lack of interest),
the sense of bitterness arising from being neglected, and feelings of anger. A failed encounter may even lead to treatment failure.

The concept of ‘encounter’ lacks a consistent definition. In addition to diagnosing and treating, an encounter involves the aspect of how healthcare professionals meet the patient; that is, how their preconceptions and attitudes affect their behaviour (Schmidt et al., 2020). Snellman et al. (2012) have identified attributes associated with a meaningful encounter. A healthcare professional’s personal qualities (being understanding, calm, empathetic) can improve the patient’s trust towards the healthcare professional and reduce anxiety. Mutual respect, being taken seriously, providing support, and making sure there is enough time for communication and receiving sufficient information are valued in patients’ conceptualisations of meaningful encounters. (Snellman et al., 2012.) The concept of encounter includes, for example, involving the patient in their care, understanding the patient’s current personal situation, sensitivity to the patient’s needs, and empathy. An encounter provides the patient with a way for expressing their needs and concerns. A nurse’s positive approach during encounters increases patients’ confidence in the nurse’s competence. (Holopainen et al., 2019.) The contextual factors of delivering care (e.g. the complexity of patients or the availability of resources) have a significant impact on how a patient encounter is viewed (Macdonald, 2007). Adequate time to familiarise oneself with the patient (Macdonald, 2007) and being present (Holopainen et al., 2014) are needed to ensure a positive encounter.

2.6 Considering frequent attenders’ perceptions in the organization of care

Although several attributes have been found to be associated with FAs, each FA has individual needs and they cannot be considered as a homogenous patient group for whom services can be arranged in a non-variant way (Hujala & Lammintakanen, 2018). How FAs’ needs are taken into consideration in the arrangement of (health)care may also affect increased service needs. The focus of research has, however, been on register-based research, with no acknowledgement of FAs’ own perceptions.

There are differences in how healthcare systems try to respond to FAs’ needs. In Finland, one of the aims of health and social services is to improve services for FAs. Evidence shows that there are diverse ways to arrange FAs’ care. For example, there are differences in how multiprofessionalism or patient involvement have been
accounted for in care (Vehko et al., 2018). In over one half of cases of FA care, no one coordinates the care process (Vehko et al., 2018) and there is a lack of consideration for FAs’ overall situations (Alahuhta & Niemelä, 2017). In about one quarter of cases, a physician-nurse pair coordinates the care process, with a solo physician in 11% of cases and a solo nurse in 9% of the cases (Vehko et al., 2018). Based on interviews with healthcare professionals and leaders, the responsibility of care coordination lies with healthcare professionals, a named nurse or the patients themselves (Alahuhta & Niemelä, 2017). Although multiprofessional care is often needed due to FAs’ complex needs, information may not be adequately exchanged, which hampers the coordination of care (Smeets et al., 2020).

For FAs, individual care is arranged through actions such as case management and individualised care plans. Case management (where a case manager plans and coordinates a patient’s care based on individual needs, and collaborates with other healthcare professionals) has been identified as a successful way to reduce unnecessary healthcare visits for FAs (Hudon et al., 2016). Individualised care plans in emergency care reduce lengths of stay in inpatient care, visits and costs (Fertel et al., 2019). Care plans are made for patients who require care coordination (e.g. FAs). A care plan aims at assessing care needs and setting goals for care with the patient using a patient-centred approach. (Komulainen et al., 2011.) However, only 30% of social and healthcare professionals indicated that a care plan is made for FAs in collaboration with the patient (Hujala et al., 2019).

Previous quantitative studies have examined how the arrangement of care affects frequent attendance. Even if a physician and FA have a strong patient-physician relationship, it does not seem to affect the increased use of services (Dinkel et al., 2016). Similarly, interpersonal communication with a physician does not seem to correlate with frequent attendance (Hudon et al., 2016). FAs more rarely have negative perceptions of physicians (Little et al., 2001). Based on Ganguli et al’s (2017) case study, a collaborative patient-physician relationship may reduce costs resulting from frequent attendance. No difference has been found in FAs’ and non-FAs’ perceptions of trust in physicians, nor in the quality or availability of care (Sandoval et al., 2010). Low satisfaction with care has been found to be associated with FAs (Koskela et al., 2010).

Burns (2017) argues that if a patient uses a lot of primary healthcare services, it is associated with an increased use of emergency care, because access to emergency care is considered easier. In emergency care, frequent attendance is associated with primary healthcare accessibility issues and problems in coordination of care (Hudon et al., 2016). However, in Cunningham et al’s (2017)
study, no correlation was found between primary healthcare accessibility issues and emergency care FAs, although FAs more often reported unmet primary care needs. According to a study conducted in the United States, 61% of emergency care FAs reported that they consulted emergency care because it was considered the only option for getting appropriate treatment for their condition. Meanwhile, 42% of FAs considered it would not be useful to consult a primary care physician. (Birmingham et al., 2016.) However, compared to patients with fewer visits to healthcare, FAs were less likely to believe that a re-consultation would be needed in order to receive proper treatment (Little et al., 2001). FAs reported that they would benefit most from the option to receive out-of-hours care for minor health issues, or from having a nurse available to help with their care needs (Birmingham et al., 2016).

### 2.7 Summary of literature

Several characteristics have been identified that explain frequent attendance, but the reasons for attending are various and individual. Thus, it is necessary to examine how healthcare is able to respond to FAs’ diverse care needs. Frequent attendance is often temporary and it is important to target research towards responding to patients with increased and long-term care needs.

Patient-centredness emphasises an individual and participative approach in patient care and considers not only medical but also broader factors, which may affect a patient’s health condition. Some definitions of patient-centredness consider wider organisational aspects, while others focus more on how patient-centredness is implemented during the consultation. In this dissertation, the wider approach for patient-centredness is assessed first, followed by the consultation-focused approach (i.e. how patient-centredness is implemented in patient-professional interaction). An encounter is considered a deeper level of interaction, providing a more comprehensive view of FAs’ experiences.
3 Purpose, aim and research questions

The purpose of this study was to describe and explain long- and short-term frequent attenders’ perceptions of patient-centredness, interaction and encounters with healthcare personnel in primary healthcare. The aim of the study was to increase knowledge of frequent attenders’ individual and diverse healthcare needs and perceptions of healthcare services, to use it in enhancing the ability of healthcare services and professionals to improve the care provided to frequent attenders. The research questions were as follows:

1. Which characteristics differentiate long-term FAs from short-term FAs? (original publication I)

2. What kinds of perceptions do long- and short-term FAs have of patient-centredness?
   2.1. How do long-term FAs’ perceptions of patient-centredness differ from those of short-term FAs? (original publication II)
   2.2. Is the factor structure of the Patient-Centred Primary Care instrument equivalent for long- and short-term FAs? (original publication II)
   2.3. How are long- and short-term FAs’ background characteristics associated with patient-centredness? (compilation)

3. What kinds of perceptions do long- and short-term FAs have of interaction with healthcare professionals?
   3.1. How do long-term FAs’ perceptions of interaction with healthcare professionals differ from those of short-term FAs? (original publication III)
   3.2. Is the factor structure of the Patient-Professional Interaction Questionnaire equivalent for long- and short-term FAs? (original publication III)
   3.3. How are long- and short-term FAs’ background characteristics associated with patient-professional interaction? (compilation)

4. How do FAs experience their encounters with healthcare personnel? (original publication IV)
4 Materials and methods

Table 1 presents the research process of the study according to the original publications. The answers to research questions 2.3 and 3.3 (see chapter 3) are only reported in the compilation and are presented separately in the table.

<table>
<thead>
<tr>
<th>Research process</th>
<th>Performance of the study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Original publication I</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Purpose of the study</strong></td>
<td>To compare the characteristics of middle-aged long- and short-term FAs</td>
</tr>
<tr>
<td><strong>Study design</strong></td>
<td>Cross-sectional cohort study</td>
</tr>
<tr>
<td><strong>Data collection</strong></td>
<td>Data from the Northern Finland Birth Cohort 1966 study’s 46-year follow-up study to identify the characteristics of study participants. Data from Finnish national register data on outpatient visits in the Care Registers for Social Welfare and Health Care to determine use of healthcare services. Data was collected in 2012.</td>
</tr>
<tr>
<td><strong>Study participants</strong></td>
<td>Long-term FAs (n=132), short-term FAs (n=645), and non-FAs (n=3,613).</td>
</tr>
<tr>
<td><strong>Data analysis</strong></td>
<td>Cross-tabulation, Pearson’s chi-squared test, Mann-Whitney U test, and univariate and multivariate binary logistic regression analyses.</td>
</tr>
<tr>
<td><strong>Original publication II</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Purpose of the study</strong></td>
<td>To compare long- and short-term FAs’ perceptions of patient-centredness</td>
</tr>
<tr>
<td><strong>Study design</strong></td>
<td>Cross-sectional study design, survey</td>
</tr>
<tr>
<td><strong>Data collection</strong></td>
<td>Postal survey, The Patient-Centred Primary Care instrument. Data was collected in January–July 2020.</td>
</tr>
<tr>
<td><strong>Study participants</strong></td>
<td>Long-term FAs (n=234), short-term FAs (n=261).</td>
</tr>
<tr>
<td><strong>Data analysis</strong></td>
<td>Cross-tabulation, Pearson’s chi-squared test, Mann-Whitney U test, multigroup confirmatory factor analysis.</td>
</tr>
<tr>
<td><strong>Original publication III</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Purpose of the study</strong></td>
<td>To compare long- and short-term FAs’ perceptions of patient-professional interaction</td>
</tr>
<tr>
<td><strong>Study design</strong></td>
<td>Cross-sectional study design, survey</td>
</tr>
</tbody>
</table>
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4.1 Cross-sectional cohort study (original publication I)

4.1.1 Study setting

In order to compare the characteristics of long- and short-term FAs, cross-sectional data from the 46-year follow-up study of the Northern Finland Birth Cohort 1966...
The study was started in the provinces of Lapland and Oulu in 1966, where expectant mothers with due dates during the year 1966 were recruited. A total of 12,058 children and their parents were included in the study, comprising 96% of all births in the area. Data was collected from the cohort members at the ages of 1, 14, 31, and 46 years through questionnaires and clinical examinations. (Nordström et al., 2022.)

The 46-year follow-up data was collected in 2012. As part of the cohort data collection, four postal questionnaires and an invitation to participate in a clinical examination were sent to 10,331 living cohort members with a known postal address in Finland. The questionnaires were: Economic, working life and resources survey; Background, lifestyle and health survey; Opinions and experiences; Supplementary questions. The questionnaires requested information about factors such as lifestyle (nutrition, smoking, physical activity, sleep), health (e.g. psychiatric symptoms, diagnosed diseases), mental resources, medication, financial situation and work. A total of 7,146 responses (response rate of 69.2%) to all of the questionnaires were received, with totals varying between 5,643 and 6,834 (response rate of 54.6–66.2%) for each part of the questionnaires. (Nordström et al., 2022.)

4.1.2 Data collection

For this study’s purposes, only cohort members meeting the following criteria were included: a cohort member’s information on use of public primary healthcare services was available from the national register (Finnish Institute for Health and Welfare); the cohort member had provided written consent; the cohort member had used (according to the information received from the national register) public primary healthcare services in 2013–2016.

The data used here consisted of the following NFBC1966 data collected in the 46-year follow-up study: income, education, satisfaction with the current life situation, marital status, gender, self-reported health and chronic health conditions. Health-related quality of life was assessed using a validated 15D instrument (Sintonen, 2001). It acknowledges 15 dimensions related to health-related quality of life: mobility, vision, hearing, breathing, sleeping, eating, speech, excretion, everyday activities, mental function, discomfort and symptoms, depression, distress, vitality, and sexual activity. Each dimension contains five ordinal levels, of which the respondent is asked to choose the level that best describes their present health status. The overall health-related quality of life was assessed through the
total 15D score. Also separate dimensions were assessed. The range of the index score ranges from 0 to 1, where 0 corresponds to death and 1 corresponds to “full” health-related quality of life. In order to determine the 15D score, a response was required to each of the dimensions. In order to replace fewer than four missing values, a missing value procedure (which the developer of the instrument had developed for this very purpose) was used (Sintonen, 2022.)

Chronic health conditions were self-reported in the questionnaire. Of the chronic health conditions reported, those belonging to the International Classification of Diseases (ICD-10) were considered, resulting a total of 56 chronic health conditions (e.g. diabetes and cancer) being included. Multimorbidity was defined as having two or more chronic health conditions. Alcohol problems and depression were handled as separate health conditions.

In order to determine the FA status of cohort members and to examine their use of outpatient public primary healthcare services, statistics were obtained from THL, the Care Registers for Social Welfare and Health Care. The definition of long-term FA that was used was based on the quantity of healthcare services used during 2013–2016: the cohort member had used healthcare services at least eight times a year, and this high use lasted for three or four years. For a short-term FA, this high use of services (at least eight times a year) had lasted for one to two years. If a cohort member had used healthcare services during 2013–2016 but attendance rates per year were lower than eight times a year, they were considered non-FAs.

4.1.3 Data analysis

In order to compare long- and short-term FAs, cross-tabulation and Pearson’s chi-squared test were used. For health-related quality of life (assessed using the 15D instrument), mean, standard deviations and the Mann-Whitney U test were used. In order to determine the factors that distinguish long-term FAs from short-term FAs, univariate and multivariate binary logistic regression analysis were used. In model 1, short-term FAs and non-FAs were compared (non-FAs being the reference group). In model 2, long-term FAs and non-FAs were compared (non-FAs being the reference group). In model 3, any FAs and non-FAs were compared (non-FAs being the reference group). In model 4, short- and long-term FAs were compared (short-term FAs being the reference group). Factors identified as statistically significant in the univariate binary logistic regression analysis were included in the further multivariate binary logistic regression analysis. Statistical significance was p < 0.05. IBM SPSS Statistics version 24 was used to analyse the data.
4.2 Cross-sectional survey (original publication II, III, compilation)

4.2.1 Study setting

In Publications II and III, long- and short-term FAs’ perceptions of patient-professional interaction and patient-centredness were compared. In the compilation, long- and short-term FAs’ characteristics associated with patient-centredness and patient-professional interaction were identified. For these purposes, cross-sectional survey data was collected from long- and short-term FAs.

The study was conducted in one city with approximately 200,000 citizens. The social and healthcare centres provide publicly available primary care services for citizens. The services provided include, for example, physician, nurse, dental care, rehabilitation, and social care services. The study participants were identified from the city’s social and healthcare centres patient records by the city’s research service personnel.

4.2.2 Data collection

The survey population of the study comprised long- and short-term FAs who were randomly selected from the social and health services patient record. The following inclusion criteria were used: the patients were either short- or long-term FAs, and they were at least 18 years of age. In order to define FA status, the number of healthcare visits during the years 2016–2019 was considered. In line with original publication I, a long-term FA was defined as a patient who had used healthcare services at least eight times during a year, and this frequent attendance had lasted for at least three years out of the four follow-up years (2016–2019). A short-term FA was defined as a patient who had used healthcare services at least eight times during the past year, had visited healthcare during the past six months, and was not defined as a long-term FA.

Power analysis was used to determine the sample size. The following values were used: power level=0.80; p=0.05; effect size=0.3. The response rate was estimated to be 40%. (Munro, 2005). Thus, the minimum sample size was calculated as 300.

In total, 750 postal questionnaires were sent to long-term FAs in January 2020. A reminder was sent in February 2020. For short-terms FAs, 750 postal questionnaires were sent in April–May 2020. A reminder was sent in June–July.
2020. A total of 234 long- and 261 short-term FAs were included (the response rate was 31.2% for long- and 34.8% for short-term FAs).

The postal questionnaire consisted of three sections: the patient-centred primary care (PCPC) instrument; the patient-professional interaction questionnaire (PPIQ); and questions related to sociodemographic factors. The questionnaires were translated from English into Finnish using forward translation and expert-panel back-translation (WHO, 2022).

The PCPC instrument (Cramm & Nieboer, 2018) included a total of 36 items with eight dimensions: patients’ preferences (7 items); physical comfort (5 items); coordination of care (4 items); continuity and transition (4 items); emotional support (4 items); access to care (5 items); information and education (4 items); family and friends (3 items). A five-point scale from 1 (totally disagree) to 5 (totally agree) was used.

The PPIQ (Casu et al., 2019) included a total of 16 items with four dimensions: effective communication (4 items); interest in patient’s agenda (4 items); empathy (4 items); patient involvement in care (4 items). A five-point scale from 1 (not at all) to 5 (very much) was used.

Socio-demographics were assessed using questions about gender, age, education and occupational status.

4.2.3 Data analysis

Frequencies and percentages were used to describe the sociodemographics for short- and long-term FAs, and Pearson’ chi-squared test was used for comparison of the sociodemographics. Statistical significance was set at p < 0.05.

To compare short- and long-term FAs’ perceptions of patient-professional interaction (PPIQ instrument) and patient-centredness (PCPC instrument), sum variables were created based on the instrument dimension. The 16 items from the PPIQ instrument were used to make four sum variables (the instrument contains four dimensions), and the 36 items from the PCPC instrument were used to make eight sum variables (the instrument contains eight dimensions).

To describe the distribution of short- and long-term FAs’ answers over the sum variables (i.e. the subscales of the instruments), mean value with standard deviation (SD) was calculated for each subscale. The Mann-Whitney U test was used to analyse whether there was a statistically significant difference between short- and long-term FAs’ answers in the given subscales. The Mann-Whitney U test was considered an appropriate analysis method because of the skewness of the data.
which was tested with the Shapiro-Wilk test. A Shapiro-Wilk test value of \( p < 0.05 \) indicated that the data was not normally distributed, and thus the Mann-Whitney U test should be used to compare the groups. In the Mann-Whitney U test, the level of statistical significance was set at \( p < 0.05 \). Cohen’s \( d \) (effect size) and confidence intervals (CI 95%) were assessed in order to determine clinical significance. Cohen’s \( d \) values were considered as follows: \( d = 0.8 \) (large clinical significance); \( d = 0.5 \) (medium); \( d = 0.2 \) (small) (Cohen, 1988). IBM SPSS Statistics version 24 was used to analyse the data.

Because the dimensions (i.e. the factor structure) for the used instruments have been identified in the previous studies (Casu et al., 2019; Cramm & Nieboer, 2018), it was examined whether the previously found factor structures can be verified in this data, with long- and short-term FAs. Multigroup confirmatory factor analysis (MGCFA) was used to examine whether the two FA groups interpreted the instruments and the items of the instruments in a similar way. MGCFA tests the measurement invariance across the two FA groups, and determines model fit for the groups. Using MGCFA we can conclude that if measurement invariance does not exist, it cannot be said whether the differences between the groups are caused by actual differences between the groups or by the structure of the scales. MGCFA starts (in chapter 5 where the results are presented, the first step is referred to as Model 1) by testing the factor structure of a given instrument separately for the groups (configural invariance). If the factor structure indicates a good fit, it is examined whether the factor loadings are also similar. Thus, secondly (Model 2), metric invariance is tested by constraining the factor loadings to be the same in the groups. If there is no statistically significant difference between the first and the second model, metric invariance is found, and it is examined whether the groups’ answers to the items of the instrument are similar. Thus, thirdly (Model 3), scalar invariance is tested by constraining the item intercepts to be the same in the FA groups. If there is no statistically significant difference between the third and second models, scalar invariance is found. Fourthly (Model 4), residual invariance is tested; the sum of the variance for the item that is not shared with the factor and error variance is similar across groups. (Milfont & Fischer, 2010.)

The following fit indexes were used for assessing the model fit: chi-squared (\( \chi^2 \)) (Byrne, 2001), \( \chi^2/df < 5 \), Tucker-Lewis fit index (TLI > 0.90) (Hu & Bentler, 1999), comparative fit index (CFI > 0.90), Root mean square error of approximation (RMSEA < 0.08) (Browne & Cudeck, 1992) and chi-squared (\( p > 0.05 \)) (Byrne, 2001).
To assess the changes in fit indexes between the models, the following values were considered: chi-squared (p > 0.05), $\Delta$CFI $\leq$ -0.01, $\Delta$gamma hat = -0.001, McDonald’s Noncentrality Index ($\Delta$McDonald’s NCI = -0.02) (Cheung & Rensvold, 2002). The data was analysed using IBM SPSS AMOS software.

In order to identify the background characteristics of long- and short-term FAs, correlated with patient-professional interaction and patient-centredness (the sum variables), Spearman’s correlation was used. Statistical significance was set at 0.05.

4.3 Systematic review (original publication IV)

4.3.1 Data collection

In original publication IV, FAs’ experiences related to encounters with healthcare personnel were synthesised based on previous research. Systematic review of qualitative studies was used as study method.

The systematic review was conducted according to JBI guidelines (Lockwood et al., 2020). A prior protocol for conducting the systematic review was developed (not published) and the review was conducted accordingly. The PICoS mnemonic was used in the development of the research question, inclusion and exclusion criteria (Lockwood et al., 2020). Here, P (population) refers to FAs, I (phenomenon of interest) to encounters between FAs and healthcare personnel, Co (context) is healthcare, and S (study design) is qualitative studies. The inclusion and exclusion criteria are presented in Table 2 according to PICo. No exclusion criteria were set based on the healthcare context; studies conducted e.g. in specialised healthcare, primary health and emergency care were considered. Only qualitative studies were included in order to gain a deeper understanding of FAs’ experiences. Also, JBI guidelines recommend conducting a systematic review separately for qualitative studies (Lockwood et al., 2020).
Table 2. Inclusion and exclusion criteria for studies. (Modified from Original publication IV)

<table>
<thead>
<tr>
<th>PICoS</th>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>P (population)</td>
<td>adult frequent attenders, frequent attenders’ experiences were examined</td>
<td>frequent attender sub-population (e.g. underaged frequent attenders, frequent attenders with mental health problems)</td>
</tr>
<tr>
<td>I (phenomenon of interest)</td>
<td>encounters between frequent attenders and healthcare personnel</td>
<td>reasons for seeking care</td>
</tr>
<tr>
<td>Co (context)</td>
<td>healthcare</td>
<td>other than healthcare</td>
</tr>
<tr>
<td>S (study design)</td>
<td>original research, qualitative study, full text available</td>
<td>case study</td>
</tr>
</tbody>
</table>

The search was conducted in three phases: preliminary, final, and manual search. Development of the search strategy, specification of the inclusion and exclusion criteria started with a preliminary search in the Scopus and CINAHL databases, where studies relevant to the research question were identified. From the studies identified in the preliminary search, keywords used in title, abstract and keywords were identified.

An information specialist was consulted in the development of the final search strategy. The databases used were PsycARTICLES, PubMed (Medline), CINAHL and Scopus. Grey literature was searched from MedNar. Due to varying terminology used for FAs, search terms related to frequent attendance were combined using proximity operators: (repeat* OR high* OR frequent* OR heav*) W3 (hospitali* OR cost* OR visit* OR use* OR attend* OR consult* OR utili*”). To identify studies related to encounters, search terms such as expect* or participat* or involve* or relations* were used in Scopus. In CINAHL, also CINAHL Subject Headings (MH) were used, e.g. “continuity of patient care”, “decision making, patient” and “patient attitudes”. Search terms related to context were not used, because terms related to FAs were considered to include the healthcare context. Adding the term “healthcare” might have reduced the number of relevant results. Also, a wide range of terms related to healthcare (e.g. emergency care and primary care) should have been considered when conducting the search strategy.
Studies were identified in the database search (n=4,469) and through other sources (n=2). The studies were imported to RefWorks, where duplicates were omitted, resulting in 1,794 studies. Two independent researchers screened the studies based on titles and abstracts. Studies which fulfilled the inclusion criteria were selected for further reading; 20 full texts were assessed according to the inclusion criteria. A manual search was conducted by screening the included studies’ (n=7) reference lists.

Critical appraisal was conducted according to the JBI critical appraisal checklist for qualitative research (Lockwood et al., 2020). In order for a study to be included in the review, it had to score a minimum of five out of ten possible critical appraisal scores. One of the studies was excluded based on critical appraisal. The results of the critical appraisal are provided in Supplement 1.

4.3.2 Data synthesis

After studies were selected, the data was extracted from the included studies. The information included was year, country and first author of the study, key findings, purpose of the study, and methodology.

According to JBI suggestions for qualitative systematic reviews, the data was synthesised using meta-aggregation (Lockwood et al., 2020). In meta-aggregation, levels of credibility are assessed between the included studies’ findings and illustrations (direct quotations from the qualitative data used in the included study) supporting a presented finding. For this purpose, verbatim findings from the included studies were extracted. In order to assess the level of credibility, only findings for which a supporting illustration was provided were included. After this, levels of credibility were assessed based on congruence between the finding and the supporting illustration. The level of plausibility was assessed as unsupported, equivocal or unequivocal, where ‘unequivocal’ indicated highest level of plausibility and ‘unsupported’ a lack of plausibility. Unsupported findings (where the provided illustration for the finding did not support the finding) were not included in the synthesis. (Lockwood et al., 2015.)

Next, categories were developed based on the similarities in the findings’ content. For a category to be created, at least two findings had to be included. Lastly, synthesised findings were developed based on similarities in the categories’ content. As in the previous phase, at least two categories had to be included in order to develop one synthesised finding. (Lockwood et al., 2015.) The meta-aggregation process is presented in Figure 4 (see section 5.4.2).
As part of the meta-aggregation approach, ConQual approach was used to rate the confidence of synthesised findings. The ConQual score is calculated separately for each synthesised finding formed in the previous synthesis process. The synthesised finding can be scored as very low, low, moderate, or high. First, each of the synthesised findings receives a ‘high’ score, and the scoring may downgrade based on dependability scoring or level of credibility scoring. Dependability scoring is based on five question scores received in the critical appraisal (Q2–Q4, Q6, Q7). Credibility scoring is based on the levels of credibility assessed in a previous phase of the study based on congruence between the finding and the supporting illustration. (Munn et al., 2014.)
5 Results

5.1 Characteristics associated with long- and short-term frequent attenders

Original publication I compared the characteristics of long- and short-term FAs. The participants’ characteristics are reported in Table 3. Prevalence of alcohol problems and depression are reported only in the compilation. A total of 4,390 cohort members met the inclusion criteria. Of them, 3.0% (n=132) were long- and 14.7% (n=645) were short-term FAs. Compared to short-term FAs, long-term FAs had more frequent multimorbidity (p<0.001), depression (p<0.001), alcohol problems (p<0.001), self-reported poor health (p<0.001), lower income (p<0.001) and lower education (p=0.007). Long-term FAs also more often reported dissatisfaction with their current life situation (p<0.001) and being divorced or unmarried (p<0.001), compared to short-term FAs. Relative to long-term FAs, short-term FAs were more often female (p<0.001). Employment status was not found as statistically significant (p=0.567)

In health-related quality of life (15D instrument), a statistically significant difference was found in mobility between long- (0.95±SD 0.14) and short-term (0.98±SD 0.08) FAs (p=0.026).

Based on univariate binary logistic regression analysis, within every one of the four models, statistical significance was found in the following characteristics: self-reported health, depression, dissatisfaction with the current life situation, and marital status. In the first model, managing everyday activities, female gender, multiple chronic health conditions, alcohol problems, and basic education were statistically significantly associated with short-term FAs. In the second model, associated with long-term FAs were multiple chronic health conditions, alcohol problems and high income. Based on the third model (association with any FAs), discomfort and symptoms, managing everyday activities, 15D, multiple chronic health conditions, female gender, low income, alcohol problems, and basic education. In model 4, mobility and high income indicated an association with long-term FAs compared to short-term FAs.
Table 3. Short- and long-term FAs’ characteristics. (Modified from Original publication I).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Short-term FAs</th>
<th>Long-term FAs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=645</td>
<td>n=132</td>
</tr>
<tr>
<td></td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td>Number of chronic health conditions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 or more</td>
<td>71.9 (464)</td>
<td>78.0 (103)</td>
</tr>
<tr>
<td>1</td>
<td>15.2 (98)</td>
<td>9.1 (12)</td>
</tr>
<tr>
<td>0</td>
<td>7.9 (51)</td>
<td>5.3 (7)</td>
</tr>
<tr>
<td>Depression</td>
<td>18.9 (122)</td>
<td>31.8 (42)</td>
</tr>
<tr>
<td>Alcohol problem</td>
<td>6.0 (39)</td>
<td>9.1 (12)</td>
</tr>
<tr>
<td>Self-reported health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>11.0 (71)</td>
<td>20.5 (27)</td>
</tr>
<tr>
<td>Decent</td>
<td>38.1 (246)</td>
<td>44.7 (59)</td>
</tr>
<tr>
<td>Good</td>
<td>43.9 (283)</td>
<td>22.7 (30)</td>
</tr>
<tr>
<td>Satisfaction with the current life situation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>14.9 (96)</td>
<td>23.5 (31)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>77.2 (498)</td>
<td>65.2 (86)</td>
</tr>
<tr>
<td>Cannot tell</td>
<td>0.9 (6)</td>
<td>1.5 (2)</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>15.0 (97)</td>
<td>6.1 (8)</td>
</tr>
<tr>
<td>Middle</td>
<td>52.2 (337)</td>
<td>61.4 (81)</td>
</tr>
<tr>
<td>Low</td>
<td>12.2 (79)</td>
<td>17.4 (23)</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>3.1 (20)</td>
<td>0.8 (1)</td>
</tr>
<tr>
<td>Disability pension</td>
<td>1.6 (10)</td>
<td>1.5 (2)</td>
</tr>
<tr>
<td>Other reason outside of workforce</td>
<td>3.3 (21)</td>
<td>3.0 (4)</td>
</tr>
<tr>
<td>Employed</td>
<td>49.6 (320)</td>
<td>42.4 (56)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic</td>
<td>8.8 (57)</td>
<td>12.1 (16)</td>
</tr>
<tr>
<td>Secondary</td>
<td>60.9 (393)</td>
<td>57.6 (76)</td>
</tr>
<tr>
<td>Tertiary</td>
<td>22.3 (144)</td>
<td>18.2 (24)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>14.6 (94)</td>
<td>17.4 (23)</td>
</tr>
<tr>
<td>Unmarried</td>
<td>11.6 (75)</td>
<td>16.7 (22)</td>
</tr>
<tr>
<td>Married/Cohabiting</td>
<td>70.0 (432)</td>
<td>56.1 (74)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>63.7 (411)</td>
<td>60.6 (80)</td>
</tr>
<tr>
<td>Male</td>
<td>36.3 (234)</td>
<td>39.4 (52)</td>
</tr>
</tbody>
</table>

In order to compare the groups, cross-tabulation and Pearson’s chi-squared test were used.
The characteristics found to be statistically significant in the univariate binary logistic regression analysis were included in the multivariate binary logistic regression analysis. Based on the results, self-reported poor health differentiates both long- and short-term FAs from non-FAs. Managing everyday activities and female gender are associated with short-term FAs, while depression and being divorced are associated with long-term FAs when compared to non-FAs. When comparing short- and long-term FAs, self-reported poor health, high income (preventive characteristic), and depression seem to be associated with long-term FAs in particular.

5.2 Frequent attendance and patient-centredness

In original publication II, long- and short-term FAs’ perceptions of patient-centredness were compared and the equivalence of the factor structure of the patient-centred primary care instrument in long- and short-term FA groups was examined. Correlation between long- and short-term FAs’ characteristics and patient-centredness was examined only in the compilation.

5.2.1 Participant characteristics

The data consisted of long- (n=234) and short-term FAs’ (n=261) answers to questionnaires. Short-term FAs were more often 60 years or older (80% vs 75%, p=0.001). Among short-term FAs it was more common to be retired due to years of employment or age (71% vs 60%), while long-term FAs were more often retired due to other reasons (23% vs 12%, p< 0.001). Gender (p=0.128) and education (p=0.055) did not seem to be statistically significantly associated with frequent attendance.

5.2.2 Long- and short-term frequent attenders’ perceptions of patient-centredness

Long- and short-term FAs’ perceptions of patient-centredness, considering individual items of the PCPC instrument, are presented in Table 4. A statistically significant difference was found in the PCPC instrument overall and within all the sub-scales. Overall, long-term FAs’ perceptions of patient-centredness were lower in relation to short-term FAs. In the sub-scales ‘Information and education’ and ‘Family and friends’, a statistically significant difference was found for every one
of the individual items. In sub-scales ‘Access to care’, ‘Continuity and transition’, ‘Coordination of care’ and ‘Patients’ preferences’, a statistically significant difference was found in nearly every one of the individual items. In sub-scale ‘Emotional support’, a statistically significant difference was found in one half of the items. In sub-scale ‘Physical comfort’, a statistically significant difference was found in one item.

Table 4. Long- and short-term FAs’ responses to individual items and sub-scales of the PCPC instrument.

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean (SD) Long-term FAs</th>
<th>Mean (SD) Short-term FAs</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCPC instrument</td>
<td>3.32 (0.93)</td>
<td>3.63 (0.83)</td>
<td>≤0.001</td>
</tr>
<tr>
<td>Patients’ preferences Item 1</td>
<td>3.46 (1.11)</td>
<td>3.75 (0.92)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 2</td>
<td>3.84 (1.12)</td>
<td>4.13 (0.91)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 3</td>
<td>3.57 (1.17)</td>
<td>3.92 (0.94)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 4</td>
<td>3.35 (1.30)</td>
<td>3.67 (1.07)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 5</td>
<td>3.38 (1.23)</td>
<td>3.72 (1.10)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 6</td>
<td>3.28 (1.32)</td>
<td>3.55 (1.13)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 7</td>
<td>3.22 (1.33)</td>
<td>3.46 (1.18)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Physical comfort</td>
<td>3.30 (1.29)</td>
<td>3.64 (1.09)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 8</td>
<td>3.63 (0.90)</td>
<td>3.81 (0.80)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 9</td>
<td>3.51 (1.25)</td>
<td>3.85 (1.11)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 10</td>
<td>2.92 (1.24)</td>
<td>3.14 (1.18)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Item 11</td>
<td>4.16 (0.84)</td>
<td>4.25 (0.80)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Item 12</td>
<td>3.47 (1.12)</td>
<td>3.59 (1.01)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Item 13</td>
<td>3.94 (1.10)</td>
<td>4.12 (0.97)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Coordination of care Item 17</td>
<td>3.30 (1.14)</td>
<td>3.61 (1.07)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 13</td>
<td>3.11 (1.37)</td>
<td>3.31 (1.24)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Item 14</td>
<td>3.47 (1.15)</td>
<td>3.69 (1.06)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 15</td>
<td>3.26 (1.33)</td>
<td>3.48 (1.31)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 16</td>
<td>3.09 (1.28)</td>
<td>3.35 (1.25)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Continuity and transition</td>
<td>3.78 (1.04)</td>
<td>4.02 (0.94)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 17</td>
<td>3.76 (1.19)</td>
<td>3.94 (1.11)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Item 18</td>
<td>3.74 (1.22)</td>
<td>4.02 (1.01)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 19</td>
<td>3.54 (1.20)</td>
<td>3.81 (1.13)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Item 20</td>
<td>3.57 (1.13)</td>
<td>3.82 (1.00)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Emotional support</td>
<td>2.66 (1.26)</td>
<td>2.90 (1.21)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 21</td>
<td>2.60 (1.36)</td>
<td>2.76 (1.28)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Item 22</td>
<td>2.72 (1.32)</td>
<td>2.98 (1.24)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 23</td>
<td>2.38 (1.34)</td>
<td>2.50 (1.25)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Item 24</td>
<td>2.62 (1.34)</td>
<td>2.89 (1.31)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item</td>
<td>Mean (SD)</td>
<td>p-value</td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>-----------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Long-term FAs</td>
<td>Short-term FAs</td>
<td></td>
</tr>
<tr>
<td>Access to care</td>
<td>3.44 (1.01)</td>
<td>3.70 (0.93)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 25</td>
<td>3.90 (1.25)</td>
<td>4.14 (1.11)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 26</td>
<td>3.31 (1.34)</td>
<td>3.58 (1.81)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 27</td>
<td>3.08 (1.34)</td>
<td>3.39 (1.31)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 28</td>
<td>2.81 (1.35)</td>
<td>3.09 (1.37)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 29</td>
<td>4.11 (1.03)</td>
<td>4.28 (0.93)</td>
<td>&gt;0.05</td>
</tr>
<tr>
<td>Information and education</td>
<td>3.63 (1.02)</td>
<td>3.95 (0.88)</td>
<td>≤0.001</td>
</tr>
<tr>
<td>Item 30</td>
<td>3.34 (1.15)</td>
<td>3.70 (0.97)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 31</td>
<td>3.52 (1.11)</td>
<td>3.87 (1.00)</td>
<td>≤0.001</td>
</tr>
<tr>
<td>Item 32</td>
<td>3.75 (1.19)</td>
<td>4.00 (1.15)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 33</td>
<td>3.38 (1.23)</td>
<td>3.73 (1.12)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Family and friends</td>
<td>2.84 (1.39)</td>
<td>3.19 (1.42)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 34</td>
<td>2.85 (1.50)</td>
<td>3.21 (1.52)</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Item 35</td>
<td>2.84 (1.40)</td>
<td>3.22 (1.39)</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Item 36</td>
<td>2.82 (1.44)</td>
<td>3.11 (1.44)</td>
<td>&lt;0.05</td>
</tr>
</tbody>
</table>

Mann-Whitney U test
5-point scale 1–5, where 1=not at all, 5=very much.

5.2.3 The factor structure of the Patient-centred Primary Care Instrument and measurement invariance with long- and short-term frequent attenders

In Figure 2, the model fit of the factor structure of the PCPC instrument is presented for long- and short-term FAs. The eight-factor model seemed to satisfy a reasonable fit of the data for long- and short-term FAs. Most of the items had high standardised loadings (<0.7) on the factor they were assumed to load, indicating good convergent validity.

In Table 5, correlations between factors of the PCPC instrument are provided. A value of <0.85 indicates discriminant validity, i.e. the factors are not overlapping. About one half of the correlations indicated poor discriminant validity, but because correlations included values <0.85 it seems that the factors reflect individual characteristics. (Lee et al., 2014.)

Two fit indexes ($\chi^2$/df=2.37, RMSEA (95%CI) = 0.053(0.05–0.055)) indicated a good model fit in Model 1, which supports the hypothesised factor structure. No statistically significant difference was found between Model 1 and Model 2, which indicates that within long- and short-term FA groups the factor loadings are similar. No statistically significant difference was found between Model 2 and Model 3, i.e.
there is variation between item-specific responses of long- and short-term FAs. A statistically significant difference was found between Model 3 and Model 4, which indicates that information on the differences between long- and short-term FAs is not lost when factors are created. Fit indexes for multigroup confirmatory factor analysis are presented in Supplement 2.
Fig. 1. Model fit of the factor structure of the PCPC instrument. Standardised loadings for long-/short-term FAs.
Table 5. Correlations between factors of the PCPC instrument for long- and short-term FAs.

<table>
<thead>
<tr>
<th>Factors</th>
<th>Correlations</th>
<th>Long-term FAs</th>
<th>Short-term FAs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients' preferences ↔ Physical comfort</td>
<td></td>
<td>0.90</td>
<td>0.91</td>
</tr>
<tr>
<td>Patients' preferences ↔ Coordination of care</td>
<td></td>
<td>0.90</td>
<td>0.87</td>
</tr>
<tr>
<td>Patients' preferences ↔ Continuity and transition</td>
<td></td>
<td>0.85</td>
<td>0.89</td>
</tr>
<tr>
<td>Patients' preferences ↔ Emotional support</td>
<td></td>
<td>0.67</td>
<td>0.58</td>
</tr>
<tr>
<td>Patients' preferences ↔ Access to care</td>
<td></td>
<td>0.66</td>
<td>0.67</td>
</tr>
<tr>
<td>Patients' preferences ↔ Information and education</td>
<td></td>
<td>0.82</td>
<td>0.82</td>
</tr>
<tr>
<td>Patients' preferences ↔ Family and friends</td>
<td></td>
<td>0.44</td>
<td>0.33</td>
</tr>
<tr>
<td>Physical comfort ↔ Coordination of care</td>
<td></td>
<td>0.91</td>
<td>0.89</td>
</tr>
<tr>
<td>Physical comfort ↔ Continuity and transition</td>
<td></td>
<td>0.87</td>
<td>0.89</td>
</tr>
<tr>
<td>Physical comfort ↔ Emotional support</td>
<td></td>
<td>0.73</td>
<td>0.64</td>
</tr>
<tr>
<td>Physical comfort ↔ Access to care</td>
<td></td>
<td>0.77</td>
<td>0.67</td>
</tr>
<tr>
<td>Physical comfort ↔ Information and education</td>
<td></td>
<td>0.84</td>
<td>0.83</td>
</tr>
<tr>
<td>Physical comfort ↔ Family and friends</td>
<td></td>
<td>0.53</td>
<td>0.30</td>
</tr>
<tr>
<td>Coordination of care ↔ Continuity and transition</td>
<td></td>
<td>0.84</td>
<td>0.93</td>
</tr>
<tr>
<td>Coordination of care ↔ Emotional support</td>
<td></td>
<td>0.73</td>
<td>0.58</td>
</tr>
<tr>
<td>Coordination of care ↔ Access to care</td>
<td></td>
<td>0.68</td>
<td>0.69</td>
</tr>
<tr>
<td>Coordination of care ↔ Information and education</td>
<td></td>
<td>0.85</td>
<td>0.86</td>
</tr>
<tr>
<td>Coordination of care ↔ Family and friends</td>
<td></td>
<td>0.54</td>
<td>0.36</td>
</tr>
<tr>
<td>Continuity and transition ↔ Emotional support</td>
<td></td>
<td>0.65</td>
<td>0.56</td>
</tr>
<tr>
<td>Continuity and transition ↔ Access to care</td>
<td></td>
<td>0.73</td>
<td>0.64</td>
</tr>
<tr>
<td>Continuity and transition ↔ Information and education</td>
<td></td>
<td>0.87</td>
<td>0.83</td>
</tr>
<tr>
<td>Continuity and transition ↔ Family and friends</td>
<td></td>
<td>0.49</td>
<td>0.32</td>
</tr>
<tr>
<td>Emotional support ↔ Access to care</td>
<td></td>
<td>0.57</td>
<td>0.49</td>
</tr>
<tr>
<td>Emotional support ↔ Information and education</td>
<td></td>
<td>0.73</td>
<td>0.53</td>
</tr>
<tr>
<td>Emotional support ↔ Family and friends</td>
<td></td>
<td>0.60</td>
<td>0.41</td>
</tr>
<tr>
<td>Access to care ↔ Information and education</td>
<td></td>
<td>0.77</td>
<td>0.73</td>
</tr>
<tr>
<td>Access to care ↔ Family and friends</td>
<td></td>
<td>0.53</td>
<td>0.19</td>
</tr>
<tr>
<td>Information and education ↔ Family and friends</td>
<td></td>
<td>0.57</td>
<td>0.29</td>
</tr>
</tbody>
</table>
Correlation between long- and short-term FAs’ characteristics and patient-centredness are presented in Table 6. Long-term FAs’ male gender was very weakly positively correlated with the dimensions ‘continuity and transition’ (p=0.033) ‘information and education’ (p=0.025) and ‘family and friends’ (p=0.018) and weakly positively correlated with ‘access to care’ (p<0.001), meaning that among long-term FAs, women assessed the aforementioned dimensions more negatively compared to men. For long-term FAs, age was very weakly negatively correlated with coordination of care (p=0.005) and family and friends (p=0.029), and weakly negatively correlated with continuity and transition (p=0.002), meaning that older long-term FAs’ assessments of the aforementioned dimensions were better than those of younger long-term FAs. For short-term FAs, age was very weakly negatively correlated with patients’ preferences (p=0.037) and weakly negatively with family and friends (p=0.002), meaning that older short-term FAs’ assessments of the aforementioned dimensions were better than those of younger short-term FAs. Short-term FAs’ educational level was weakly negatively correlated with family and friends (p<0.001), i.e., the higher the short-term FAs’ educational level, the lower their assessments of the dimension ‘family and friends’. Mean comparisons for correlations identified as statistically significant are presented in Supplement 3. Correlation was not found between long- or short-term FAs and employment status.
Table 6. Correlation between long- and short-term FAs' characteristics and dimensions of patient-centredness.

<table>
<thead>
<tr>
<th>Correlation</th>
<th>Gender</th>
<th>Age</th>
<th>Education</th>
<th>Employment status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>long-term FAs</td>
<td>short-term FAs</td>
<td>long-term FAs</td>
<td>short-term FAs</td>
</tr>
<tr>
<td>Patients' preferences</td>
<td>0.064</td>
<td>-0.004</td>
<td>-0.085</td>
<td>-0.130¹</td>
</tr>
<tr>
<td>Physical comfort</td>
<td>0.065</td>
<td>0.057</td>
<td>-0.094</td>
<td>-0.046</td>
</tr>
<tr>
<td>Coordination of care</td>
<td>0.056</td>
<td>0.055</td>
<td>-0.184¹</td>
<td>-0.072</td>
</tr>
<tr>
<td>Continuity and transition</td>
<td>0.142¹</td>
<td>-0.14</td>
<td>-0.203¹</td>
<td>-0.109</td>
</tr>
<tr>
<td>Emotional support</td>
<td>0.048</td>
<td>0.053</td>
<td>-0.109</td>
<td>-0.020</td>
</tr>
<tr>
<td>Access to care</td>
<td>0.218¹</td>
<td>0.094</td>
<td>-0.059</td>
<td>0.018</td>
</tr>
<tr>
<td>Information and education</td>
<td>0.149¹</td>
<td>0.055</td>
<td>-0.123</td>
<td>0.049</td>
</tr>
<tr>
<td>Family and friends</td>
<td>0.171¹</td>
<td>0.043</td>
<td>-0.159¹</td>
<td>-0.213¹</td>
</tr>
</tbody>
</table>

¹Statistically significant. Spearman’s rho test
5.3 Frequent attendance and patient-professional interaction

In original publication III, long- and short-term FAs’ perceptions of interaction with healthcare professionals were compared and the equivalence of the factor structure of the 36-item primary care instrument in long- and short-term FA groups was examined. The study participants’ characteristics are described in section 5.2.1. Correlation between long- and short-term FAs’ characteristics and patient-professional interaction was examined only in the compilation.

5.3.1 Long- and short-term frequent attenders’ perceptions of patient-professional interaction

Long- and short-term FAs’ perceptions of patient-professional interaction, considering individual items and sub-scales of the PPIQ instrument, are presented in Table 7. In general, long-term FAs assessed patient-professional interaction more poorly compared to short-term FAs. A statistically significant difference was found for the entire PPIQ instrument. However, only in sub-scale ‘Patient involvement in care’ was a statistically significant difference found between long- and short-term FAs’ responses. In sub-scale ‘Patient involvement in care’, a statistically significant difference was found for every one of the individual items. In sub-scales ‘Interest in the patient’s agenda’ and ‘Empathy’, a statistically significant difference was found for a part of the items. For sub-scale ‘Effective communication’, a no statistically significant difference was found between long- and short-term FAs’ responses. Non-response rates for the items ranged from 3 to 13 missing responses.

5.3.2 The factor structure of the Patient-Professional Interaction Questionnaire and measurement invariance with long- and short-term frequent attenders

In Figure 3, the model fit of the factor structure of the PPIQ instrument is presented for long- and short-term FAs. The four-factor model seemed to satisfy a reasonable fit of the data for long- and short-term FAs. All of the items had high standardised loadings on the factor they were assumed to load, indicating good convergent validity. The content of the figure is provided only in the compilation.
Correlations between factors are reported in Table 8. Correlations between the factors were high (>0.85), indicating poor discriminant validity. The correlations are reported only in the compilation.

Fit indexes for multigroup confirmatory factor analysis are presented in Supplement 4. In Model 1, four out of six fit indexes indicated good model fit of the factor structure for long- and short-term FAs. Between Model 1 and Model 2, three values indicated difference. No statistically significant difference was found between Model 1 and Model 2, i.e. the factor loadings are similar within the short- and long-term FA groups. Two values indicated difference between Model 2 and Model 3. A statistically significant difference was found, meaning that there is a difference between the short- and long-term FA groups regarding their responses to the items.
<table>
<thead>
<tr>
<th>Item</th>
<th>Mean (SD)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Long-term FAs</td>
<td>Short-term FAs</td>
</tr>
<tr>
<td>PPIQ instrument</td>
<td>3.74 (1.18)</td>
<td>3.99 (1.03)</td>
</tr>
<tr>
<td>Effective communication</td>
<td>4.11 (1.02)</td>
<td>4.31 (0.83)</td>
</tr>
<tr>
<td>Item 1</td>
<td>4.00 (1.04)</td>
<td>4.16 (0.95)</td>
</tr>
<tr>
<td>Item 3</td>
<td>4.17 (1.00)</td>
<td>4.33 (0.82)</td>
</tr>
<tr>
<td>Item 6</td>
<td>4.02 (1.13)</td>
<td>4.19 (1.00)</td>
</tr>
<tr>
<td>Item 9</td>
<td>3.95 (1.18)</td>
<td>4.16 (1.02)</td>
</tr>
<tr>
<td>Interest in the patient’s agenda</td>
<td>3.68 (1.27)</td>
<td>3.92 (1.09)</td>
</tr>
<tr>
<td>Item 2</td>
<td>3.80 (1.25)</td>
<td>3.94 (1.13)</td>
</tr>
<tr>
<td>Item 5</td>
<td>3.45 (1.34)</td>
<td>3.73 (1.15)</td>
</tr>
<tr>
<td>Item 7</td>
<td>3.64 (1.36)</td>
<td>3.94 (1.12)</td>
</tr>
<tr>
<td>Item 14</td>
<td>3.41 (1.33)</td>
<td>3.79 (1.16)</td>
</tr>
<tr>
<td>Empathy</td>
<td>3.83 (1.19)</td>
<td>4.04 (1.02)</td>
</tr>
<tr>
<td>Item 4</td>
<td>3.76 (1.23)</td>
<td>3.94 (1.08)</td>
</tr>
<tr>
<td>Item 8</td>
<td>3.98 (1.15)</td>
<td>4.20 (0.97)</td>
</tr>
<tr>
<td>Item 10</td>
<td>3.32 (1.30)</td>
<td>3.63 (1.16)</td>
</tr>
<tr>
<td>Item 12</td>
<td>3.83 (1.23)</td>
<td>4.00 (1.07)</td>
</tr>
<tr>
<td>Patient involvement in care</td>
<td>3.62 (1.25)</td>
<td>3.89 (1.10)</td>
</tr>
<tr>
<td>Item 11</td>
<td>3.61 (1.30)</td>
<td>3.85 (1.20)</td>
</tr>
<tr>
<td>Item 13</td>
<td>3.50 (1.27)</td>
<td>3.80 (1.11)</td>
</tr>
<tr>
<td>Item 15</td>
<td>3.41 (1.33)</td>
<td>3.75 (1.22)</td>
</tr>
<tr>
<td>Item 16</td>
<td>3.52 (1.37)</td>
<td>3.81 (1.17)</td>
</tr>
</tbody>
</table>

5-point scale 1–5, where 1=not at all, 5=very much
5.3.3 Long- and short-term frequent attenders’ characteristics associated with patient-professional interaction (compilation)

Correlation between long- and short-term FAs’ characteristics and patient-professional interaction are presented in Table 9. No statistically significant correlation was found between long- or short-term FAs’ characteristics and patient-professional interaction.

Table 8. Correlations between factors of the PPIQ instrument for long-term and short-term FAs. (Modified from Original publication III).

<table>
<thead>
<tr>
<th>Factors Correlations</th>
<th>Long-term FAs</th>
<th>Short-term FAs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effective communication ↔ Interest in the patient’s agenda</td>
<td>0.92</td>
<td>0.94</td>
</tr>
<tr>
<td>Effective communication ↔ Empathy</td>
<td>0.99</td>
<td>1.00</td>
</tr>
<tr>
<td>Effective communication ↔ Patient involvement in care</td>
<td>0.92</td>
<td>0.94</td>
</tr>
<tr>
<td>Interest in the patient’s agenda ↔ Empathy</td>
<td>0.97</td>
<td>0.98</td>
</tr>
<tr>
<td>Interest in the patient’s agenda ↔ Patient involvement in care</td>
<td>1.00</td>
<td>0.99</td>
</tr>
<tr>
<td>Empathy ↔ Patient involvement in care</td>
<td>0.96</td>
<td>0.98</td>
</tr>
</tbody>
</table>
Table 9. Correlation between long- and short-term FAs' characteristics and patient-professional interaction.

<table>
<thead>
<tr>
<th>Correlation</th>
<th>Gender Correlation</th>
<th>Age Correlation</th>
<th>Education Correlation</th>
<th>Employment status Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>long-term FAs</td>
<td>short-term FAs</td>
<td>long-term FAs</td>
<td>short-term FAs</td>
</tr>
<tr>
<td>Effective communication</td>
<td>0.093</td>
<td>0.058</td>
<td>-0.021</td>
<td>0.025</td>
</tr>
<tr>
<td>Interest in the patient's agenda</td>
<td>0.049</td>
<td>0.032</td>
<td>0.031</td>
<td>0.011</td>
</tr>
<tr>
<td>Empathy</td>
<td>0.065</td>
<td>0.010</td>
<td>-0.043</td>
<td>-0.049</td>
</tr>
<tr>
<td>Patient involvement in care</td>
<td>0.052</td>
<td>0.043</td>
<td>0.031</td>
<td>-0.009</td>
</tr>
</tbody>
</table>

Statistically significant results were not found.
5.4 Frequent attendance and encounters with healthcare personnel

5.4.1 Study characteristics

In original publication IV, FAs’ perceptions of encounters with healthcare personnel were synthesised. The included studies’ (n=6) countries of origin were United States of America (Mautner et al., 2013; Sledge et al., 2011), Sweden (Olsson & Hansagi, 2001; Wiklund-Gustin, 2013) and the United Kingdom (Hodgson et al., 2005; Neal et al., 2000), and the studies were conducted in primary (Hodgson et al., 2005; Neal et al., 2000; Sledge et al., 2011; Wiklund-Gustin, 2013) and emergency care settings (Olsson & Hansagi, 2001). The studies were published between 2000 and 2013. From nine to 33 FAs were interviewed in the included studies, resulting in a total of 129 FAs’ experiences. All of the studies were conducted using individual interviews.

5.4.2 Encounters between frequent attenders and healthcare personnel

A total of 45 findings were extracted from the included studies. When assessing levels of credibility for the findings, eight of the findings were excluded. For four of the excluded findings, no illustration was provided (i.e. it was not possible to assess the level of credibility) and for the other four excluded findings, the provided illustration did not seem to support the presented finding. Thus, a total of 37 findings were assessed to be equivocal or unequivocal, and were included in the synthesis. The unsupported findings are provided Supplement 5.

Based on similarities in the findings’ meanings, 13 categories were developed. From these categories, the following four synthesised findings were created: 1) difficulties in resolving FAs’ situations may create service circles, making patients frustrated with their situation; 2) FAs’ own expertise should be recognised and valued alongside the expertise of healthcare professionals when performing collaborative care; 3) disparagement and a lack of empathy may make FAs feel misunderstood and unappreciated; 4) FAs should be recognised as individuals by taking their circumstances into account and providing support accordingly. The process of meta-aggregation is presented in Figure 4.
The following four synthesised findings including 13 categories were identified:

- Difficulties in resolving frequent attenders’ situations may create service circles, making patients frustrated with their situation
  
  - Frequent attenders feel they are referred from one healthcare professional to another
  
  - The care received and its outcomes do not meet frequent attenders’ expectations
  
  - Frequent attenders seek reassurance through consulting, during which the healthcare professional can significantly increase frequent attenders’ future attendance

- Frequent attenders’ own expertise on their condition should be recognised and valued alongside the expertise of healthcare professionals when performing collaborative care
  
  - Frequent attenders regard specialist-client relationships as collaborations with healthcare professionals
  
  - Frequent attenders want their own interpretation of their condition and situation to be valued and taken into consideration
  
  - Frequent attenders respect the healthcare professional as an authority and expert in managing and treating their symptoms
- Disparagement and a lack of empathy may make frequent attenders feel misunderstood and unappreciated
- Frequent attenders feel they are disrespected and stigmatised by healthcare professionals
- Frequent attenders feel they are not worth caring for
- Frequent attenders perceive a lack of empathy and their needs are disparaged
- Frequent attenders feel healthcare professionals do not understand them or their condition
- Frequent attenders should be recognised as individuals by taking their circumstances into account and providing support accordingly
- Frequent attenders appreciate having their individual situation and condition acknowledged and being treated accordingly
- Frequent attenders value healthcare professionals also acknowledging other (non-medical) aspects of their life that they consider important
- Frequent attenders emphasise the role of healthcare professionals and the clinic as a whole in making frequent attenders feel welcome

The first synthesised finding, ‘difficulties in resolving FAs’ situations may create service circles, making patients frustrated with their situation’, was formed based on three categories. 1) FAs feel they are referred from one healthcare professional to another; 2) The care received and its outcomes do not meet FAs’ expectations; 3) FAs seek reassurance through consulting, during which the healthcare professional can significantly influence FAs’ future attendance. A clear care need may not be identified during a consultation, which may lead to referrals or disruption of care and, further, to a situation where FAs feel they are left alone with their situations (Olsson & Hansagi, 2001). Several referrals between different healthcare professionals, lead to FAs feeling they do not receive adequate care (Olsson & Hansagi, 2001; Wiklund-Gustin, 2013). Although they need information on possibilities to improve their own condition (Wiklund-Gustin, 2013), FAs may feel that encounters with healthcare professionals are confusing (Olsson & Hansagi, 2001). During encounters, FAs had feelings of dissatisfaction, frustration and disappointment due to the healthcare professionals’ behaviour (Hodgson et al., 2005; Sledge et al., 2011). Healthcare professionals can affect FAs’ future consultation behaviour through their approaches. While FAs’ repeated
consultations may be a consequence of healthcare professionals’ suggestions (need for follow-up visits) (Neal et al., 2000), re-consultations are also initiated by FAs themselves, and healthcare professionals can, through their own behaviour, influence FAs’ future consultations (Hodgson et al., 2005; Neal et al., 2000). FAs may consult in order to receive a diagnosis (Neal et al., 2000) or reassurance (Hodgson et al., 2005). While receiving a diagnosis may reduce visits, it may also lead to re-consultations due to increased worries about the condition if the healthcare professionals are not able to provide satisfactory reassurance (Neal et al., 2000).

The second synthesised finding, ‘FAs’ own expertise should be recognised and valued alongside the expertise of healthcare professionals when performing collaborative care’ included three categories: 1) FAs regard specialist-client relationships as collaborations with healthcare professionals; 2) FAs want their own interpretation of their condition and situation to be valued and taken into consideration; 3) FAs respect the healthcare professional as an authority and expert in managing and treating their symptoms. FAs viewed their relationship with healthcare professional as collaborative, requiring input from both FAs themselves and the healthcare professionals (Sledge et al., 2011). FAs considered healthcare professionals as experts in making treatment decisions (Hodgson et al., 2005; Sledge et al., 2011), also noting their role as one of providing support (Neal et al., 2000). In order for the relationship to be collaborative, FAs wanted their own perceptions of their condition to be considered, but they reported feelings of not being taken seriously or healthcare professionals not considering the FA’s visit as necessary (Olsson & Hansagi, 2001; Wiklund-Gustin, 2013). FAs felt a lack of recognition of their own interpretations (Wiklund-Gustin, 2013) and need for care (Olsson & Hansagi, 2001), while healthcare professionals seemed to tell them how to feel (Wiklund-Gustin, 2013).

The third synthesised finding, ‘Disparagement and a lack of empathy may make FAs feel misunderstood and unappreciated’ consisted of four categories: 1) FAs feel they are disrespected or stigmatised by healthcare professionals; 2) FAs feel they are not worth caring for; 3) FAs perceive a lack of empathy and their needs are diminished; 4) FAs feel the healthcare professionals do not understand them or their condition. Feelings of disrespect or stigmatisation resulted from receiving the impression that healthcare professionals consider that they make an excessive number of visits and thus are nuisances or hypochondriacs (Neal et al., 2000), or that the reasons for their visits are more benefit-seeking (e.g. getting time off from work) (Wiklund-Gustin, 2013). Some FAs felt they were being a burden because
of their health condition and did not receive understanding from healthcare professionals. This resulted in feelings of unimportance or inadequacy, of not being worthy of receiving care and having to cope alone. (Wiklund-Gustin, 2013.) A lack of empathy in the approach decreased FAs’ satisfaction with care and caused stress (Olsson & Hansagi, 2001). Feelings of not being understood by healthcare professionals resulted from situations where there was a lack of recognition of te FAs’ situations and feelings. The ability to solve FAs’ problems is further complicated by their concerns not being heard. (Wiklund-Gustin, 2013.)

The fourth synthesised finding, ‘FAs should be recognised as individuals by taking their circumstances into account and providing support accordingly’ included three categories: 1) FAs appreciate having their individual situation and condition acknowledged and being treated accordingly; 2) FAs value healthcare professionals also acknowledging other (non-medical) aspects of their life that they consider important; 3) FAs emphasise the role of healthcare professionals and the clinic as a whole in making FAs feel welcome. Receiving emotional support (Mautner et al., 2013), having a meaningful relationship with the healthcare professional and recognising the FA’s individual situation were considered important (Sledge et al., 2011), although this recognition was not always regarded as adequate (Hodgson et al., 2005). Along with recognition of medical care needs, considering the social aspects of the FA’s life was valued (Sledge et al., 2011). In addition to the importance of a well-established relationship with healthcare professionals (Neal et al., 2000), FAs noted that reception staff (Hodgson et al., 2005) and the overall attitude in the clinic influences the feeling of being welcome (Olsson & Hansagi, 2001; Sledge et al., 2011).

**Confidence of synthesised findings**

Based on the ConQual summary of findings, all of the synthesised findings gave a low ConQual score, which indicates a need to critically assess the results. The synthesised findings scored low on ConQual because both the dependability and credibility downgraded the ConQual score by one level (the scoring started as high, dependability downgraded the score to moderate, and credibility downgraded the score to low). The dependability downgrade was due to two or three responses to critical appraisal criteria (Q2–4, Q6, Q7) being ‘yes’. The credibility downgrade was due to the level of credibility for the included findings being assessed.
5.5 Summary of the results

The results of original publication I indicate that self-reported poor health is a characteristic of both long- and short-term FAs, although when these groups are compared, self-reported poor health seems to be more strongly associated with long-term FAs. While depression and high income (preventive attribute) seem to be associated with long-term FAs, managing everyday activities (a dimension of health-related quality of life) and female gender are characteristics associated with short-term FAs.

In addition to distinct characteristics, it also seems that long-term FAs’ perceptions of patient-centredness and patient-professional interaction were poorer than those of short-term FAs (original publications II and III). The results indicate the importance of recognising FAs’ individual needs (original publication IV) and involving FAs in their care as active participants (original publications II–IV). Expressed empathy and effective communication during a consultation were found to be important (original Publications II and IV), although not significantly associated with long- and short-term FAs in original publication III. In addition, coordination and continuity of care were identified as part of patient-centred care in services to FAs (original publications II and IV). Among long-term FAs, young age and female gender correlated negatively with patient-centredness. Among short-term FAs, young age and high education correlated negatively with patient-centredness. No correlation was found between long- or short-term FAs and patient-professional interaction.
6 Discussion

The purpose of this study was to describe and explain long- and short-term frequent attenders’ perceptions of patient-centredness, interaction and encounters with healthcare personnel in primary healthcare. The main results are discussed in line with the research questions. In addition, the validity and reliability of the study, ethical considerations, implications of the study and suggestions for future research are discussed. The validity and reliability of the study include the assessment of the equivalence of the instruments for long- and short-term FAs, and discussion of the strengths and limitations of the study.

6.1 Discussion of the main results

Characterisation of long- and short-term frequent attenders

Based on the results, self-reported health poor was associated with both long- and short-term FAs. However, in the last model of the logistic regression analysis, long-term FAs were compared to short-term FAs, and it seemed that the chances of being a long-term FA among those with self-reported poor health were over three times those of patients with self-reported good health. While self-reported health has been related to frequent attendance in general (Kaattari et al., 2015), this study’s results are in line with a finding of Pymont and Butterworth (2015), who found that worrying about their own health was more common among long-term than short-term FAs. An explaining factor for frequent attendance is how one is able to cope with one’s health condition (Margo-Dermer et al., 2019). Previously the prevalence of psychological problems (Buja et al., 2018) and perceptions of the effects of the current health condition on one’s life (Brodeur et al., 2020; Kivelä et al., 2018; Kolk et al., 2021; LaCalle & Rabin, 2010; Strömbom et al., 2019) have been found to be associated with FAs. Self-reported health can also include psychological, physical and social dimensions, all of which are associated with FAs (Kivelä et al., 2018). Also in this study, depression seemed to be associated with long-term FAs. Difficulties in accessing mental health services may lead to FAs consulting other healthcare professionals in primary care without adequate education on mental health issues, which might require specialised care (Smeets et al., 2020).

The results of this study were not in line with the assumption of health-related quality of life being associated with FAs, although, for example, a poor health
condition and its effects on life may cause feelings of dissatisfaction with life (Kivelä et al., 2018). Managing everyday activities seemed to be associated only with short-term but not long-term FAs. In contrast, moderate activities can be affected by long-term FAs’ health conditions (Pymont & Butterworth, 2015), although no association has been found with the 15D instrument measuring health-related quality of life (Koskela et al., 2010). While identifiable chronic health conditions can be objectively interpreted as ‘acceptable’ reasons to attend, the causes of FAs’ multiple visits can be more complex, leading to poor perceptions of health. For FAs with medically unexplained symptoms, anxiety about health and possible misdiagnosis cause worries and normal tests may not provide sufficient reassurance (Dwamena et al., 2009).

**Patient-centredness assessed by frequent attenders**

Long-term FAs’ perceptions of patient-centredness in general and the dimensions included were poorer than those of short-term FAs. The result is in line with a previous finding, where long-term FAs’ assessments of patient satisfaction were lower than those of short-term FAs (Koskela et al., 2010), and it was speculated whether the finding might be due to the fact that low satisfaction with care resulting from not receiving satisfactory responses to their health-related questions (Koskela, 2008). The dimension of ‘patient’s preferences’ included aspects of recognising a patient’s individual needs and involving the patient in care decisions. The success of care can be dependent on how the patient’s own perceptions regarding the effects of care on their life are taken into consideration (Langberg et al., 2019). It should be noted that FAs’ goals for care are not stable and can alter along with changing circumstances and priorities (Wyman et al., 2020). On the other hand, especially in cases where care has long-term impacts on a patient’s life, shared decision-making should be made use of (Joosten et al., 2008). If FAs have unexplained medical symptoms, it can be challenging to identify the core reason for symptoms and to provide adequate care. In addition to a ‘standard set’ of examinations, physicians may organise additional tests to provide reassurance for the patient. (Warner et al., 2017.) Simultaneously, FAs with medically unexplained symptoms may demand additional tests and complain if their requests are not answered (Dwamena et al., 2009). FAs with multiple health and social issues are able to seek care when needed but may have difficulties in adhering to care (Ylitalo-Katajisto et al., 2018).

The finding of the study regarding low assessment of ‘information and education’ includes providing adequate information on care to the patient and
enabling communication between the patient and the healthcare professional. A patient’s own active role also promotes the healthcare professional’s activity in sharing information (Cegala et al., 2007). Incomprehensible communication leads to misunderstandings between patients and healthcare professionals (Ganguli et al., 2017), although clear information is a prerequisite for a FA to participate in their care (Roh & Park, 2016). Currently in Finland, information technology does not support (due to incompatibility of systems) information sharing between professionals and sectors, which also hampers the coordination of FA care (Alahuhta & Niemelä, 2017; Hujala & Lammintakanen, 2018).

Coordination of care among healthcare professionals, and continuity of care across healthcare sectors were assessed as low, a finding that supports previous studies. While FAs experience coordination problems (Hudon et al., 2016), through continuity of care the number of required healthcare visits can be decreased (Barker et al., 2017). An adequate number of healthcare professionals and the stability of healthcare professionals improve patient-centredness (Hower et al., 2019). FAs often require multiprofessional care due to the complexity of their health issues (Hujala et al., 2019; Ylitalo-Katajisto, 2019). Hujala and Lammintakanen (2018) emphasise that a multiprofessional approach is essential, as no single social or healthcare professional can help an FA alone. In Finland, social and healthcare professionals assessed that collaboration between professionals and sectors in FAs’ services is better in areas with integrated social and healthcare services, although also in these areas assessments were critical (Hujala et al., 2019). Not having a sufficient knowledge of other professionals’ work and what kind of care FAs receive from other professionals or sectors are major reasons for collaboration problems (Hujala & Lammintakanen, 2018). This may result in fragmented care and the existence of several care plans (Valtiontalouden tarkastusvirasto, 2017). Thus, healthcare professionals may not have comprehensive understanding of the patient’s situation (The Commonwealth Fund, 2017). Common ways for improving coordination and continuity of care are multiprofessional teams, case management and care/service plans (Hujala et al., 2020), of which especially case management and multiprofessional care have been found successful in FA care (Hudon et al., 2016; Mercer et al., 2015). Incorporating a multiprofessional perspective in the care plan has several positive outcomes: improvements in health, patient satisfaction and self-management, and reductions in costs of care (Hudon et al., 2019).
In patient-professional interaction, long-term FAs assessed patient involvement in care more negatively than short-term FAs. While healthcare professionals consider that the ambition exists to involve FAs in decision-making regarding their care (Alahuhta & Niemelä, 2017), in practice their views are not always adequately taken into account (Hujala et al., 2019), which is also the case for patients in general (Stiggelbout et al., 2015). Involving a FA in decisions, starting with care planning, increases commitment to care and FAs’ understanding of the requirement of their active role in the care process. Conversely, not being involved in care planning may hamper engagement in care, as the content and aims of the plan are not clear for the patient or have not been agreed. (Hudon et al., 2019.) It is common that goals for care are set by professionals (Rose et al., 2017) and a care plan is often formed on the basis of the services that are available (Poikela, 2010).

For long-term FAs in particular, prolonged need for care enables more possibilities for patient involvement (Thompson, 2007). On the other hand, if several care options are available, it is naturally more common to involve the patient in decision-making compared to a situation where clinical guidelines support one option (Pollard et al., 2015). Patients can also consider themselves unable to be involved with respect to their health condition or knowledge, and responsibility is delegated to healthcare professionals (Kaseva, 2011). Kivinen et al. (2020), however, note that although patient involvement should be enabled in healthcare organisations and by healthcare professionals during consultations, involvement is not just a possibility for the patient but also an obligation to commit to care. While patients emphasise the importance of being heard and understood as part of being involving in care, healthcare professionals simultaneously bestow responsibility upon patients as active partners (Weiste et al., 2020). The shift in patients’ roles from care receivers to active participants in their own care is somewhat problematic, because the patient simultaneously receives a more central role and more responsibility for their own care (McColl-Kennedy et al., 2017). In practice, it is not possible for patients to make utterly consumeristic care choices due to a lack of self-administration competence and differences in patient’s and healthcare professional’s views as to what the prioritisation should be within care decisions, regarding the progress of diseases and the overall health situation (Hujala et al., 2014).
Encounters with healthcare personnel experienced by frequent attenders

The results of the systematic review synthesised what kinds of experiences FAs associate with encounters with healthcare personnel. Difficulties in responding to FAs’ care needs may lead to FAs ending up with ‘service circles’, which causes frustration and uncertainty for FAs. While it has been found that coordination of care is beneficial (although often lacking), particularly for patients who have complex care needs (Barker et al., 2017; Hudon et al., 2016) and require chronic disease management (Ehman et al., 2017), the results indicate that there is no entity that could coordinate the care. Due to fragmented care, FAs are required to describe their (often complex) situations repeatedly to different healthcare professionals. It is worth noting that although frequent attendance is often deemed as a burdening and unnecessary consultation behaviour, problems in care coordination are also causing excessive consultations: healthcare professionals instruct FAs to reconsult or refer them to another care provider. At the same time, FAs also reconsult in cases where a diagnosis has been received but reassurance is needed.

Involving FAs in their care as active participants was supported by this study’s results. FAs experienced a lack of recognition of their views on their situation. While FAs want to take part in their care, the care should be based on reciprocal collaboration between the FA’s own experiential knowledge (i.e. the patient is the one who has the best ability to assess if and what kind of effects the care may have on their life) and the healthcare professional’s competence. Acknowledging the patient’s personal experience improves healthcare professionals’ awareness of the overall situation (Street, 2017) and the success of care (Langberg et al., 2019), while a lack of it hampers the shared understanding of the patient’s current situation (Smucker et al., 2001). Interpretations of a FA’s situation are inadequate and a shared understanding between the FA and the healthcare professional is not formed if the FA’s concerns and view’s on their health are not taken into consideration (Smucker et al., 2001).

In line with the results of original publication II, a lack of empathy was identified as an aspect of encounters between FAs and healthcare professionals. The experience of not receiving empathy and of facing disparagement may lead to feelings of being misunderstood. Aspects other than the medical aspects of care were also considered important, emphasising the importance of empathy in the relationship with a healthcare professional (Derksen et al., 2017). Focusing on medical aspects is common (Mjaaland et al., 2011), especially when there is a need to make a diagnosis efficiently (Roh & Park, 2016), while emotional issues are
avoided in spite of patients’ concerns (Mjaaland et al., 2011). This hampers understanding of the patient’s situation and possibilities of solving the patient’s problems (Derksen et al., 2017). Conversely, it has been found that even if a healthcare professional believes that no particular progress is achieved in the patient’s care, the patient may consider the relationship successful because the professional showed dedication to helping the patient (Ratanawongsa et al., 2011). Disparagement appeared in that FAs interpreted healthcare professionals to consider their visits unnecessary. Salokekkilä (2011) notes that from a patient’s point of view, an unnecessary visit results from a situation where the patient is unable to discuss the matters that concern them with the healthcare professional. For the patient, this may cause feelings of frustration when they are not being heard. If a concern they wanted to have acknowledged during the consultation is not taken into consideration, the visit seems unnecessary for the patient. (Salokekkilä, 2011.)

Finally, the results indicate that a FA’s individual situation should be considered and support provided accordingly. Long-term care relationships make it easier to respond to this challenge, as healthcare professionals are familiar with the patient’s situation and excessive consultation time does not have to be used up informing the healthcare professional about past issues (Waibel et al., 2012). The patient’s individual situation comprises not only medical health aspects but also other dimensions of life, i.e. the biopsychological context; the biological, psychological and social situations (Street, 2017). As part of managing medical conditions, it is necessary to take into account concerns initiated by the patient, even if the healthcare professional’s views differ as to which concerns are relevant to prioritise (Grant et al., 2013).

Patient-centredness and associated characteristics of frequent attenders

The study provided novel information on FAs’ characteristics associated with patient-centredness. An association was found between age and gender. Age seemed to have a correlation with aspects of patient-centredness; elderly FAs’ assessments of patient-centredness were better compared to younger FAs (however, it should be noted that the high number of elderly FAs may have affected this finding). Older age is a significant explaining factor for frequent attendance, as increasing age often entails chronic health conditions requiring care. Older FAs may appreciate the social dimension of consultations more, and feelings of loneliness may result in frequent consulting (Welzel et al., 2017). Elderly patients seem to show more gratitude towards the received care (Nilsen et al., 2022) and
they often have a more traditional view of care, where healthcare professionals are leading experts and the patient’s role is somewhat passive (Hestevik et al., 2019). Of older patients, 85% prefer shared decision-making or more independence in making care-related decisions with a physician. Elderly patients who delegate health activities (e.g., manage medicine or measure blood pressure) are more likely to make shared care decisions or leave decision-making to the physician. (Wolff & Boyd, 2015.)

Women’s assessments of patient-centredness were lower than men’s among long-term FAs. Women consult healthcare professionals more often for physical and mental health reasons (Thompson et al., 2016), which may be explained by the fact that, compared to men, women have poorer perceptions of their health (Gil-Lacruz & Gil-Lacruz, 2010). FAs are often women and female gender is associated with long-term frequent attendance in particular (Koskela et al., 2010; Pymont & Butterworth, 2015). Also previous studies have identified that women have poorer perceptions of care. Women’s perceptions of receiving adequate information on test results or accessing care in a timely manner are poorer than men’s (Chen et al., 2022). The finding of women’s poorer perceptions of patient-centredness may be due to the fact that they have higher expectations of consultations and their outcomes. Women who demonstrate a greater trust in physicians seem to consult more often when having physical symptoms (Thompson et al., 2016). Cameron et al. (2010) found that although older women contact a physician as much as men do, women seemed to receive fewer physicians’ services despite similar care needs. Previous studies have not found an association between patient-centredness and gender but it seems that when both the patient and the healthcare professional are women, perceptions of patient-centredness are improved (Bertakis & Azari, 2012). It should be noted that there were more women among study participants.

6.2 Validity and reliability of the study

6.2.1 Cross-sectional cohort study

Using a wide (n=4,390) population-based cohort study, data is an essential strength of the study. The NFBC1996 data contains a wide range of information on health and welfare. However, in contrast to self-collected data, using existing cohort data defined which variables were examined for the purposes of identifying FAs’ characteristics. Because all the study participants were 46 years old, the results can
be generalised to middle-aged FAs. Also, the Finnish context may restrict the generalisability of the results to international settings.

The information was self-reported by study participants. Although for example self-reported health is suitable for self-reporting, the fact that the prevalence of chronic health conditions was self-reported is a limitation of this study. The number of healthcare visits the participants had made was based on information obtained from the Finnish national register data on outpatient visits in the Care Registers for Social Welfare and Health Care, i.e. the information is objective. It should be noted that although THL has collected data on outpatient primary care since 2011, information may be inadequate due to insufficient reporting. However, in this study information was used from the years 2013–2016, and the degree of reporting has increased during the years after the data collection was started.

6.2.2 Cross-sectional survey

Good psychometric properties have previously been found for both of the used instruments (Casu et al., 2019; Cramm & Nieboer, 2018). The internal consistency of the instruments and the included subscales were assessed by Cronbach’s alpha. For both instruments, the Cronbach’s alpha values were considered satisfactory ($\geq 0.7$) (Bland & Altman, 1997): 0.96 for the PCPC instrument and 0.79–0.95 for the subscales of the PCPC instrument; 0.98 for the PPIQ instrument and 0.93–0.95 for the subscales of the PPIQ instrument.

The MGCFA indicated good model fit for the previously identified factor structure for both questionnaires and justified comparing long- and short-term FAs. PPIQ and PCPC had good convergent validity but poor discriminant validity. With the PCPC instrument (original publication II), MGCFA was conducted further (until residual invariance) than with the PPIQ instrument (original publication III), which indicates that the PCPC is a more divisive instrument when comparing long- and short-term FAs. In addition, the PPIQ instrument has not previously been tested using MGCFA. Due to various conceptualisations of patient-centredness and the complexity of FAs’ care needs, it is important to consider how the used instruments seemed to identify these nuances. The dimensions that were found statistically significant when comparing long- and short-term FAs in original publication II (all of the dimensions) and original publication III (involvement in care) identify the dimensions of involvement in care (Thompson, 2007; Weiste et al., 2020) and the wider organisational perspective of patient-centredness. However, the results of the original publication IV indicate that the used instruments may not exhaustively
identify the nuances of FAs’ service needs: for example, experiences of disparagement and being misunderstood. Also, the fact that services are fragmented, that FAs need several health services, and the hectic nature of the primary healthcare setting challenge the instruments’ abilities to provide comprehensive information (Ylitalo-Katajisto, 2019). Overall, the assessment of patient involvement is difficult because a patient’s perceptions are subjective and attached to the situation at hand (Kivinen et al., 2020; Leenmann & Hämäläinen, 2016).

Despite the fact that a reminder questionnaire was sent, the response rate was relatively low: 31.2% (n=234) for long-term and 34.8% (n=261) for short-term FAs. Based on the power analysis, the minimum sample size was estimated at 300. However, a minimum sample size of n=200 has been suggested to be adequate for statistical power for data analysis (Hoe, 2008; Kline, 2005).

Different definitions are used for frequent attendance. While many previous studies only consider visits to physicians, this study also took into account visits to nurses in the definition. In Finland, nurses have significant responsibilities in primary care, such as treatment and serving as the first point of contact for patients (Maier & Aiken, 2016). Considering the difference between long-term and temporary frequent attendance is a strength of this study, as the focus of previous studies has been on frequent attendance in general, i.e., the perspective of changing over time has not been taken into account.

When identifying FAs, only visits to primary healthcare were considered. FAs in healthcare often also have a need for social services (Ylitalo-Katajisto, 2019). From the viewpoint of the upcoming Finnish health and social services reform, which aims at integrating social and healthcare services, acknowledging the need for social care services would have been beneficial. The study participants were identified from the city’s patient record, and because the city in question provides social and healthcare services from the same centre, it would have been possible to take into account visits to social care. However, the aim of the study was to examine FAs’ perceptions of patient-centredness and patient-professional interaction with healthcare professionals. Also, the instruments used in this study only considered healthcare professionals.

Regarding the generalisability of the results, this study has some limitations. Most of the study participants were elderly and female, which may hamper the generalisability of the results. In addition, the results may not be directly generalisable to other healthcare settings nationally (different ways of organising care) or internationally.
In the PPIQ instrument, questions related to perceptions of the most recent consultation, while the PCPC instrument assessed perceptions from the last six months. The fallibility of human memory may affect the reliability of self-reported information (Schacter, 1999). Also, due to the cross-sectional study design, various perceptions of FAs’ consultations have not been identified.

### 6.2.3 Systematic review

The development of the search strategy started with an initial search, where studies relevant to the review were identified. The studies’ titles, abstracts and key words were screened, and based on the screening, appropriate search terms were identified. The search strategy was developed with assistance from an information specialist. In addition to the database search, MedNar was used for searching grey literature.

The systematic review was conducted according to the guidelines of the JBI for systematic reviews of qualitative evidence and the JBI qualitative critical appraisal criteria was used when assessing the quality of the studies. Also, a ConQual score was calculated for the synthesised findings. Although the ConQual score was low, the scoring indicates the quality of the included studies. In reporting, Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was used where applicable. For example, assessing risk of bias was not applicable because only qualitative studies were included. Data synthesis was first made by the first author and agreed upon with other authors. Critical appraisal was done by two authors.

The systematic review only included six articles and was conducted during 2000–2013. The research strategy and the databases used may not have identified all the relevant studies. A considerable limitation of the review is the fact that the included studies focused mainly on encounters with physicians. Thus, the results cannot be directly generalised to other healthcare professional groups. On the other hand, this indicates a need for further studies, where relations between FAs and other healthcare professionals are studied. The studies included in the review are relatively old, which indicates a need for more current research.

In accordance with the meta-aggregation approach, only findings with accompanying and credible illustrations were included. Thus, some of the relevant findings may have been excluded, but the approach increases the credibility of the results. It should be noted that the included studies included experiences of 129 FAs, resulting in a total of 37 findings to be included in the synthesis. The number of findings may be considered problematic. Because at least two findings are...
needed to form a category and, further, two categories are needed to form a synthesised finding, a lack of included findings may lead to ‘forced’ categories, i.e. there are not enough findings to provide satisfactory number of categories. On the other hand, methodologically different qualitative studies can be included in meta-aggregation, because only findings identified by the original study authors are included in the meta-aggregation. Thus, the synthesis conducted using meta-aggregation does not violate the philosophical foundations of the included studies. (Lockwood et al., 2020).

Studies dealing with FA sub-groups (e.g. FAs with medically unexplained symptoms) were excluded. Because of the heterogeneity of FAs, in the studies included in the review there are most likely to be FA sub-groups.

### 6.3 Ethical considerations

The study was conducted according to Finnish guidelines on responsible conduct of research and procedures for handling allegations of misconduct (Tutkimuseettinen neuvottelukunta, 2012) and in accordance with the Declaration of Helsinki (World Medical Association, 2013).

Regarding original publication I, the NFBC1966 46-year follow-up study was approved by the Northern Ostrobothnia Ethical committee (94/2011). The data was handled through remote desktop with a secure internet connection. In the used data, the cohort members’ identification numbers were pseudonymised. Only information on those cohort members who had provided informed consents were included. Two separate informed consents were required: the information provided in the study can be used for research purposes in non-identifiable form, and national register information regarding the cohort members (use of healthcare services) can be incorporated to the information collected during the study.

For original publications II and III, the study was approved by the city’s Director of Healthcare. There was no need for an ethical review because the participants provided a written informed consent, the research did not intervene in study participants’ physical integrity (survey), the study participants did not include minors, participants were not exposed to exceptionally strong stimuli, the survey did not cause mental harm that exceed the limits of normal life, and the study did not threaten study participants’ safety (Finnish National Board on Research Integrity TENK, 2019; World Medical Association, 2013). Long- and short-term FAs were identified from the patient register based on healthcare visits. The information can be handed over for research purposes based on research permission...
(Act on the Openness of Government Activities 621/1999, 28§). Because of the postal questionnaire, for which the names and home addresses for study participants were needed, a personal data register was formed. In order to send a reminder to respond to the questionnaire, the questionnaires were coded by identification numbers. Thus, pseudonymised data was formed. The University of Oulu was the registrar. Only the registrar had access to personal data and only the registrar could handle the personal data in accordance with the Regulation of the European Parliament and of the Council (2016/679) and the Data Protection Act (1050/2018). Identification numbers were stored distinct from personal data. After the data was collected, the personal data was destroyed. Only information on participants who provided written informed consents alongside the returned questionnaire were used. The data was stored behind a password.

Some questions in the survey may have caused unpleasant feelings or memories for the participants (Hammer, 2017). The participants were informed that participation in the study was voluntary, they could withdraw from the study at any point and their participation or refusal did not influence the care they received. The doctoral student’s contact information was provided along with the questionnaire in case the study participants wanted to ask additional questions about the study. Permissions to use the instruments were obtained through email from the authors who developed the instruments (Casu et al., 2019; Cramm & Nieboer, 2018).

Regarding Publication IV, the publication followed the JBI guidelines for conducting a systematic review.

### 6.4 Implications of the study

The study provided novel information on patient-centredness and patient-professional interaction in FA services, and comparison of long- and short-term FAs using a survey. In addition, novel information was provided on the characteristics of long- and short-term FAs associated with patient-centredness.

The results strengthen the previous outcomes regarding the fact that healthcare services are not unequivocally able to respond to FAs’ care needs. Long- and short-term FAs provided low scores for patient-centredness and patient-professional interaction, while long-term FAs’ perceptions were poorer, a result not previously reported. Thus, adequate resources should be targeted at improving services for FAs and especially FAs with long-term healthcare needs. Most of the interventions targeted at FAs have been planned and implemented for FAs in general, without considering long-term high needs for care. The results can be used in identifying
long-term FAs and in developing interventions especially for long-term FAs. Because of long-term FAs’ poorer assessments – and probably longitudinally gained experiences due to long-term frequent attendance – it would be beneficial to use their experiential knowledge of care organisation in developing services.

The results of this study add knowledge of the characteristics that differentiate long- and short-term FAs. Although some previous studies aiming at finding these differences have used somewhat similar definitions for long- and short-term FAs, the results provided differentiating results. This further emphasises the need for using a consistent definition for long- and short-term FAs in order to identify the characteristics that are common to long- and short-term FAs in different FA populations and healthcare settings, i.e. to obtain generalisable results on the phenomenon.

The Finnish health and social reform aims at improving patient-centredness and FA care. This study provides information on the current state of perceptions that FAs have on the services and can be used in developing the services. The results can be used in providing more information on patient-centredness in FA services for healthcare professionals and management who have central roles in implementing patient-centredness (Moisanen, 2018). Healthcare professionals should pay more attention to recognising FAs’ own expertise as part of care and considering their individual circumstances when planning care. Healthcare professionals have a pivotal role in the perceptions that FAs relate to consultations and healthcare services overall, through providing support and enabling FAs’ involvement in care planning, decision-making and implementation. This could potentially decrease unnecessary consultations and turn the focus of FAs’ visits to a one that better corresponds to needs.

The results of the study provide important information for the purposes of customer segmentation in healthcare and healthcare service assessment. According to the results, customer segments should consider FAs with prolonged healthcare needs. Customer segmentation is also used in healthcare, providing a tool for knowledge-based management (Koivisto et al., 2020; Ylitalo-Katajisto, 2019). Customer segmentation was originally developed for the business sector, where services are tailored according to different customer segments’ needs (Smith, 1956). Although certain characteristics seem to be associated with FAs and can explain higher care needs, which can be used in customer segmentation, the results emphasise the need for assessing how the provided care responds to FAs’ needs. Long-term FAs assessed patient-centredness and patient-professional interaction more negatively than short-term FAs. Thus, the care provided may not be adequate
in relation to long-term FAs’ care needs. Also, FAs seem to be quite a heterogenous patient group and care should acknowledge this individuality. Although customer segmentation serves knowledge management and identification of FAs, at the practical level the emphasis should be on assessing how patient-centredness, patient-professional interaction and patient encounters are achieved.

The results of original publication IV provided important qualitative insight on encounters between FAs and healthcare professionals, which can be used in developing instruments for assessing FAs’ perceptions of the organisation of care. Factor structures of previously developed instruments for assessing patient-centredness and patient-professional interaction were confirmed in this study. It is important to test the applicability of previously developed instruments to different participant groups and contexts through structural validity assessment and validation (Hudon et al., 2011; Köberich & Farin, 2015). This study provided information on the applicability of the used instruments for FAs in Finnish primary healthcare. MGCFA is more common in the field of sociology, for example, but less so in health sciences and health management science. It provides a justification for comparing two groups and thus should be conducted prior to comparison analyses (Milfont & Fischer, 2010). Instruments can be used in assessing whether through interventions it is possible to affect long- and short-term FAs’ perceptions of patient-centredness and patient-professional interaction and whether their perceptions differ. While several interventions have been targeted at FAs, assessing their effects on how FAs’ perceptions of consultation experiences have changed is not as common (van den Heede & van de Voorde, 2016).

6.5 Suggestions for future research

1. The results focus on healthcare professionals’ roles during consultations, while the recognition of how FAs can take more active part in their care is somewhat lacking, i.e. how FAs for their own part aim at enhancing their participation during consultations instead of leaving the responsibility to healthcare professionals. Along with the shift to seeing patients more as healthcare consumers, there is a need for taking into account this change in patients’ roles in future research and instrument development.

2. The instruments used in this study also have versions developed for healthcare professionals (Cramm & Nieboer, 2017; Gremigni et al., 2016), which would enable paired comparisons between FAs and healthcare professionals’ perceptions of patient-centredness and patient-professional interaction.
3. The NFBC1966 study’s extensive follow-up data collections merged with THL’s register data on outpatient visits (the Care Registers for Social Welfare and Health care) can be used in examining changes in FA status over time and following changes in FAs’ comprehensive wellbeing.

4. Digital healthcare services are useful, e.g. in managing chronic health conditions, and have gained an increasing role, especially with the COVID-19 pandemic, also in FA services (Kestilä et al., 2020). As far as it is known, current instruments measuring patient-centredness do not take into account this change in providing services, and it would be important to develop instruments which would also consider the digital healthcare setting.

5. Considering the upcoming health and social services reform and FAs’ needs for health, social and employment services, an examination of frequent attendance that recognises wider service needs and developing instruments measuring these service needs would be beneficial.
7 Conclusions

Based on the results of the study, the following conclusions can be presented:

1. Long-term and short-term FAs have different characteristics and thus should be recognised as separate patient groups. Self-reported poor health seemed to be more strongly associated with long-term FAs.

2. Long-term FAs’ perceptions of patient-centredness and patient-professional interaction were poorer compared to short-term FAs, emphasising the need to focus especially on developing long-term FAs’ care.

3. The PCPC and PPIQ instruments indicated goodness-of-fit in long- and short-term FA groups in the primary healthcare setting. Based on MGCFA, the instruments are suitable for comparing the two FA groups.

4. During consultations, FAs should be involved in decision-making, and their views and situations should be considered when planning and providing care.
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Hudon, C., Sanche, S., & Haggerty, J. L. (2016). Personal Characteristics and Experience of Primary Care Predicting Frequent Use of Emergency Department: A Prospective Cohort Study. *PLOS ONE, 11*(6), e0157489. https://doi.org/10.1371/journal.pone.0157489


Supplements

Supplement 1. Critical appraisal of the included studies. JBI Critical Appraisal Checklist for Qualitative Research was used.

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<td>9</td>
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<td>No</td>
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<td>Yes</td>
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<td>Yes</td>
</tr>
</tbody>
</table>

Total scores 6 7 6 8 6 10

Q1: Is there congruity between the stated philosophical perspective and the research methodology?
Q2: Is there congruity between the research methodology and the research question or objectives?
Q3: Is there congruity between the research methodology and the methods used to collect the data?
Q4: Is there congruity between the research methodology and the representation and analysis of data?
Q5: Is there congruity between the research methodology and the interpretation of the results?
Q6: Is there a statement locating the researcher culturally and theoretically?
Q7: Is influence of the researcher on the research, and vice-versa, addressed?
Q8: Are participants, and their voices, adequately represented?
Q9: Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate authority?
Q10: Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
**Supplement 2. Multigroup confirmatory factor analysis fit indexes for the PCPC instrument. (Modified from Original publication II).**

<table>
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<tr>
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<th>Model 1</th>
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<th>Difference (Model 2 vs. Model 3)</th>
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<td>Difference (Model 2 vs. Model 3)</td>
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<th>Continuity and transition</th>
<th>Emotional support</th>
<th>Access to care</th>
<th>Information and education</th>
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## Supplement 4. Multigroup confirmatory factor analysis fit indexes for the PPIQ instrument.

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<td>RMSEA (95% CI)</td>
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<td>0.052 (0.049-0.055)'</td>
<td>0.051 (0.049-0.054')</td>
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Supplement 5. The unsupported findings not included in data synthesis.

<table>
<thead>
<tr>
<th>Illustration</th>
<th>Finding (a verbatim extract of the study authors’ interpretation)</th>
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</thead>
<tbody>
<tr>
<td>&quot;I had a doctor treat me in the ER. I was having chest pains. And I was told I was drug addict and it was in my head. And a week later I had a massive heart attack. I also explained to him that every young black person that walks in the hospital is not seeking drugs. That some of us do actually have problems. We may not know what they are, but they’re real. And every female doesn’t imagine she’s sick.&quot;</td>
<td>Participants described difficult encounters with health care providers (not the Care Management Team). More than one half of participants (n = 12) related stories of encounters that had upset them; several explicitly mentioned withdrawing from outpatient providers by choosing not to attend appointments with those providers as a result. Over a third of participants switched providers because of dissatisfaction with those relationships. Others who had not switched chose not to follow a given provider’s instructions as a result of these negative interactions.</td>
</tr>
<tr>
<td>“And I actually thought I was dying, and that is the reason half the time when I was ill I wouldn’t go to the doctors.”</td>
<td>There was a very real fear of consulting inappropriately (either too soon or too late in the natural history of an illness) and consequently meeting the GP’s disapproval or being labelled as a nuisance or a hypochondriac.</td>
</tr>
<tr>
<td>“Oh it were regular. I would say, with the 'flu and things like that, bad backs, monthly, sometimes twice, three times a month. Bad backs, bad shoulders. I have had injections in my shoulders, I have had pains in my knees, pains in my back, sometimes I have not been able to walk, I have had to come downstairs on my bum. What else were I going with? Thumping headaches, really thumping headaches, I was forever getting 'flu and it went to my chest, and I was forever having asthma. I was really ill and I was frightened.”</td>
<td>Most of the short bursts described by the burst/gap frequent attenders (for example, several consultations over a few weeks) were for episodes of illnesses; most included a significant amount of the GP’s influence over the need to reconsult.</td>
</tr>
</tbody>
</table>
Illustration: “Okay. So they’re helpful by coming to see you, following up with you and then also just sort of knowing what you need.”
Mr. Issacs: “Yeah and I like the fact that they take the time and talk to my mom and tell her everything. They call her and tell her this is what’s going on. This is what type of test we’re going to give him. I’m pleased with that.”
Interviewer: “Okay. What are some things that have happened that weren’t so helpful with your doctors?”
Mr. Issacs: “Well when I had the surgery in September, I was trying to reach the doctor’s office and even … his secretaries weren’t very helpful in (nearby town). They weren’t compassionate and I had to let ‘em know, so I had to call (his office) and let those nurses know that I didn’t appreciate that … Because if you’re not compassionate, it turns me off. I pull back. I mean, I’ll still be nice, but the kind of person that will quickly pull back.”

A personal-oriented participant sums up some qualities of the personal-oriented perspective and points up some of the rewards and risks of this paradigm.
Original publications


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Original publications are not included in the electronic version of the dissertation.
1684. Kivelä, Milja (2022) Childhood risk factors for young adult strokes : the Northern Finland Birth Cohort Study 1966
1685. Länsitie, Miia (2022) Fyysisen aktiivisuuden ja paikallaanoloon yhteydet iäkkäiden henkilöiden sokeriaineenvaihduntaan sekä sydän- ja verisuonisairauksien ja kuoleman riskeihin : väestöpohjainen Oulu45-kohorttitutkimus
1686. Balogun, Hamudat Abiodun Ahmed (2022) Environmental and nutritional determinants of adverse pregnancy outcomes
1687. Hänninen, Nina (2022) Relaxation anisotropy of quantitative MRI parameters in biological tissues
1688. Tarkanen, Tarja (2022) Kuvantamisen potilasturvallisuus : vaara-, haitta- ja läheltä piti -tilanteet Suomen kuvantamiskeskuksinä
1689. Mazumder, Atiqul (2022) Alcohol use, alcohol polygenic score and cognition in schizophrenia, schizoaffective disorder, bipolar disorder, and a middle-aged birth cohort
1690. Saunajoki, Anni (2022) Association of one-hour post-load glucose in an oral glucose tolerance test with type 2 diabetes and its related complications
1691. Lumme, Johanna (2022) Vitamin D status in Northern Finland Birth Cohort 1966 and in women with reproductive disorders
1692. Paalimäki-Paakki, Karoliina (2022) 360°-ohjausympäristön vaikutus sekelvaltimonen tietokonetomografiatutkimukseen tulevien potilaiden ahdistukseen
1694. Pirkainen, Paula (2022) Kouluutusinterventio vaikutus hoitojenklikönnön haasteelliseksi kokeman käättäytymisen esiintyvyyteen, hoitojenklikönnön toimintatapoihin sekä osaamiseen muistisairaiden henkilöiden tehostetussa palveluasumisessa
1695. Laajala, Anne (2022) Caries experience among adults in Northern Finland : association with oral hygiene and genetic factors
1696. Tiensuu, Heli (2022) Genetic and other biological factors behind spontaneous preterm birth : genetics, transcriptomics and proteomics of human spontaneous preterm delivery

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Moona Huhtakangas

LONG- AND SHORT-TERM FREQUENT ATTENDERS IN PRIMARY HEALTHCARE – PERCEPTIONS OF PATIENT-CENTREDNESS, INTERACTION AND ENCOUNTERS WITH HEALTHCARE PERSONNEL